

[REDACTED]
[REDACTED]
Date 30 September 2026
Your Ref FOI-2026-3471
Our Ref FOI-2026-3471

Enquiries to [REDACTED]
Email psd.foi@nhs.scot

Dear [REDACTED]

Freedom of Information Reference FOI-2026-3471

I refer to your Freedom of Information (Scotland) Act 2002 (FOISA) request that we received on 3 September 2026. We have now completed the search of our records and can provide you with the following information:

Please confirm whether your organisation has assessed the total costs of neuromuscular services it commissions and what those costs were in the past four financial years (including estimated costs if definitive figures not available).

For UK Specialist Services commissioned through NHS England, please provide the total pooled funding provided by Public Services Delivery Scotland / National Services Scotland in the year 2022-23, 2023-24, 2024-25, and 2025-26 for:

Diagnostic service for rare neuromuscular disorders (adults and children)

Under [Section 17 of FOISA for "Information not held"](#) National Services Directorate (NSD), part of Public Services Delivery Scotland (PSD Scotland), commissions specialist diagnostic and genomic testing arrangements for patients with suspected disorders through nationally commissioned laboratory and genomic pathways. However, NSD does not hold information on:

- Total pooled funding provided by PSD Scotland specifically for rare neuromuscular diagnostic services in the financial years noted.
- The cost of individual diagnostic tests.
- Costs attributable to specific rare neuromuscular disorders.

Any costs are typically held by the provider NHS Health Boards (HBs) and laboratories delivering the services and are not centrally recorded by NSD. For more information you may wish to contact the individual HBs directly using the email addresses listed below, as under the terms of FOISA we are unable to transfer this request on your behalf.

Chair Mr Keith Redpath
Chief Executive Professor Karen Reid

- foi@ggc.scot.nhs.uk
- loth.freedomofinformation@nhs.scot
- tay.foisa@nhs.scot
- gram.foi@nhs.scot
- nhsh.foirequestshighland@nhs.scot

McArdle's disease service (adults and children)

Lysosomal storage disorders service (children and adults). If possible, please provide the figure specifically for Pompe disease. If not, please provide the total figure.

Under [Section 17 of FOISA for "Information not held"](#) PSD Scotland does not hold specific Pompe disease figures, the Inherited Metabolic Diseases Service covers Lysosomal Storage Disorders including Pompe disease. Financial information is held at whole service level and it is not possible to disaggregate the costs.

Some patients with Lysosomal Storage Disorders, McArdle's Disease and rare neuromuscular disorders who require specific clinical expertise which is unavailable in Scotland are referred to national services commissioned by NHS England. NSD acts as the administrator of a financial risk sharing arrangements from which costs of these referrals are met. NSD can provide the following cost details:

	2022/23	2023/24	2024/25	2025/26
Lysosomal Storage Disorder	£44,853	£55,635	£62,374	-
Lysosomal Storage Disorder (children)	£2,039	£2,703	£8,480	£9,618
McArdle's Disease	-	£2,319	£65,651	£118
Rare neuromuscular disorders	£6,928	£55,370	£38,814	£63,377

For other specialist neuromuscular services, please confirm the commissioning process and funding provided in the year 2022-23, 2023-24, 2024-25, and 2025-26 for:
Rare mitochondrial disorders service (adults and children)

Under [Section 17 of FOISA for "Information not held"](#) PSD Scotland does not hold the requested information. Specialist services for patients with rare mitochondrial disorders are supported through nationally commissioned specialist and genomic diagnostic arrangements where clinically appropriate. Funding is not routinely allocated or reported on as a separate standalone service budget for rare mitochondrial disorders.

Specialist neuroscience services for spinal muscular atrophy (children)

Under [Section 17 of FOISA for "Information not held"](#) PSD Scotland does not hold the requested information. Children with suspected or confirmed spinal muscular atrophy may access specialist neuroscience and neurology clinical services regionally and genomic diagnostic services through nationally commissioned pathways. Any costs associated with delivery of genomic testing are held by the provider NHS HBs and laboratories delivering the services and are not centrally recorded by NSD.

Screening for spinal muscular atrophy has been introduced as a pilot as part of the newborn blood spot screening programme. The screening pathway supports earlier identification and referral of affected infants into specialist clinical services. Funding for the newborn screening pilot is

provided separately by Scottish Government and NSD does not hold a discrete annual funding value for the pilot.

For more information you may wish to contact the individual HBs directly using the email addresses listed in our answer to Q1 above, as under the terms of FOISA we are unable to transfer this request on your behalf.

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.

Under [Section 17 of FOISA for "Information not held"](#) does not hold the requested information. There are no nationally commissioned services for neuromuscular care and therefore we cannot provide nor approximate on the spend which is incurred by HBs or Local Authorities.

For more information you may wish to contact the individual HBs directly using the email addresses listed in our answer to Q1 above, as under the terms of FOISA we are unable to transfer this request on your behalf.

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

Under [Section 17 of FOISA for "Information not held"](#) PSD Scotland does not hold the requested information. NSD does not commission neurology services in Scotland.

Please confirm whether the Public Delivery Services Scotland / National Services Scotland 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.

Under [Section 17 of FOISA for "Information not held"](#) PSD Scotland does not hold the requested information. The commissioning of neurological services is the responsibility of HBs. For more information you may wish to contact the individual HBs at the addresses listed under our answer to Q1 above.

Note: For any new national services commissioned or existing services, feedback is sought from relevant patient advocacy groups, third sector organisations and charities.

Where information not held by PSD Scotland may be found:

Further information may be available from regional centres for Neuromuscular conditions which are hosted by NHS Greater Glasgow and Clyde, NHS Lothian, NHS Tayside, NHS Grampian and NHS Highland.

For more information you may wish to contact the individual HBs directly using the email addresses listed in our answer to Q1 above, as under the terms of FOISA we are unable to transfer this request on your behalf.

There is also an outreach service to NHS Lanarkshire from NHS Greater Glasgow and Clyde.

I trust you will find the information of assistance and if you require any further information, please do not hesitate to contact me using the email address psd.foi@nhs.scot

If you are unhappy with any aspect of how we have dealt with your request, you can make representations to us asking us to review the handling of your request. Please write to the Associate Director Corporate Governance using the email address psd.foi@nhs.scot within 40 working days of the date of this correspondence.

If after a review you are still unhappy, you also have the right to apply to the Scottish Information Commissioner, who can be contacted at Kinburn Castle, St Andrews, Fife, KY16 9DS, or via their [online Appeal form](#).

Yours sincerely,

