

9 October 2025

Our Ref: FOI 1406

Dear

**Freedom of Information Act 2000
Information in Relation to Genetic Testing For Motor Neurone Disease**

I am writing to confirm that the South Eastern Health & Social Care Trust (the Trust) has now completed its search for information relating to the above, which you requested on 11 September 2025.

A response to the questions you have raised has been provided by the Medicine, Unscheduled Care and Cancer Directorate and is attached in Appendix A.

If you are unhappy as to how this request has been handled, you have the right to seek a review within the Trust in the first instance. You should write to the Information Governance Department, Lough House, Ards Community Hospital (informationgovernance@setrust.hscni.net) within two months of the date of this response and your complaint will be considered and a response provided, within 20 working days of receipt.

If, after receiving a response, you remain unhappy, you can refer your complaint to the Information Commissioner at The Information Commissioner's Office –Northern Ireland, 3rd Floor, 14 Cromac Place, Belfast, BT7 2JB. It is important to note that if you refer any matter to the Information Commissioner, you will need to show evidence of having gone through the Trust's internal review procedure to try to resolve the matter with the Trust in the first instance.

If you have any queries about this letter, please do not hesitate to contact me. Please remember to quote the reference number above in any future communications.

Yours sincerely

Olivia Robinson
Information Governance Officer

I would be grateful if you could provide the following information in relation to patients diagnosed with MND under the care of your Trust:

Q1. Please provide the number of MND patients referred by your Trust to the Clinical Genetics Service for genetic testing in 2023/24 and 2024/25.

A1. The Trust does not hold this information. However, the Clinical Genetics Service located within The Belfast Health and Social Care Trust (Belfast Trust) may be able to help with this request. You can contact the Belfast Trust at publicliaison@belfasttrust.hscni.net.

Q2. Please provide details of any counselling services available locally to MND patients and their families in relation to genetic testing, including:

- a. Whether counselling is provided before and after testing***
- b. Which professionals deliver the service***
- c. How patients are referred***

Q3. What is the average waiting time to access such counselling services for MND patients and their families within your Trust area?

A2-3. The Trust is unable to provide this information as there is no established psychological service available to support MND patients and their families in relation to genetic testing.