

30 September 2025

Genetic Testing for Motor Neurone Disease (MND)

- 1. Please provide the number of MND patients across Northern Ireland who were referred to the Clinical Genetics Service for genetic testing in 2023/24 and 2024/25. If available, please break this down by referring Health and Social Care Trust.**

<10 from each Trust.

- 2. Please outline the clinical pathway for MND patients in relation to genetic testing, including referral procedures and the point at which patients are offered genetic testing.**

Diagnostic genetic testing for MND would mainly be offered through neurology. For unaffected family members predictive testing for MND would be arranged through our department. We follow a pathway based on established practice for Huntington's disease that involves two in clinic counselling sessions before the test. Usually the first session is with a genetic counsellor (GC), patients would be triaged as urgent and seen within 9 weeks of referral. The second appointment, if patients chose to continue, would be with a GC and Consultant and booked into the next available clinic. The pathway can include additional appointments if requested by the patient. Results are always given in person.

Details of how to refer to our service are on our website – [How to make a referral to Clinical Genetics | Belfast Health & Social Care Trust website](#)

- 3. Where are genetic tests for MND processed, including:**

- 1. Northern Ireland laboratories**
- 2. Laboratories in other parts of the UK or EU**
- 3. External testing providers**

- a. Northern Ireland laboratories – Samples are processed initially through Regional Molecular Diagnostics Service and forwarded to Centogene for sequencing of all relevant genes associated with neurological conditions.
- b. Laboratories in other parts of the UK or EU – NHS England Genomic Laboratory Hubs process through their internal labs or through a sendaway process.
- c. External testing providers - unknown

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4. What is the average turnaround time for genetic testing for MND, from the point of sampling to the return of results?

25 days from receipt of sample by Centogene.

5. Please provide details of the counselling services available to MND patients and their families in relation to genetic testing, including: (Predictive testing)

1. Whether counselling is provided before and after testing-

Both two sessions before one results appointment + follow up phone call and further appointments if required e.g to discuss prenatal options

2. Which professionals deliver the service-

Genetic counsellors and Genetic Consultants

3. How patients are referred-

Self-referral forms given for relatives which can be emailed directly by patient to request appointment or through GP would be most common routes

6. What is the average waiting time to access counselling services for MND patients and their families in relation to genetic testing?

Usually an up to 9 week wait for an urgent appointment with a genetic counsellor for predictive testing