



Ref: FOIA Reference 2023/24-297

Date: 20th September 2023

Email foi@uhnm.nhs.uk

Dear

I am writing to acknowledge receipt of your email dated 11th August 2023 requesting information under the Freedom of Information Act (2000) regarding genetic testing services

As of 1st November 2014 University Hospitals of North Midlands NHS Trust (UHNM) manages two hospital sites – Royal Stoke University Hospital, and County Hospital (Stafford). Therefore the response below is for the two sites combined from that date where appropriate.

Q1 We are requesting details on what information and training resources are used by your trust to support patients, family members and staff around genetic testing in motor neuron disease (both genetic testing of people with motor neuron disease and predictive testing of family members). The information we request is listed below this email. We are interested in information on publicly available or locally produced resources. We appreciate your responses to all questions, even where the answer is 'none' or 'not relevant'. In addition, please send us copies or a link to any resources you are able to share. Please send by email to [REDACTED]

Basic information

**Q1. On behalf of which organisation and department are you answering this request?
Service**

A1 Neurology Department, MND team, UHNM NHS Trust/ North Midlands MND Care and Research Network

Q2. Do you offer genetic testing services to people with MND?

A2 Yes

**Q3. Do you offer predictive genetic testing services to at-risk relatives of people with MND?
Resources for people with MND and family members**

A3 No

Q4. What leaflets and websites do you provide (or signpost) to people with MND on genetic testing?

A4 MNDA website

Q5. What leaflets and websites do you provide (or signpost) to at-risk relatives of people with MND on predictive testing?

A5 None

**Q6. What letters, leaflets or websites do you provide to people having MND genetic testing or predictive testing to facilitate family communication?
Resources and training for staff**

A6 None

Q7. What educational resources or training do you have to support staff with MND genetic testing?

A7 MNDA website/ MNDA genetic testing FAQs information sheet

Q8. What educational resources or training do you have to support staff with MND predictive testing?

A8 None

*Please note that any individuals identified do not give consent for their personal data to be processed for the purposes of direct marketing.

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An anonymised copy of this request can be found on the Trust's disclosure log, please note that all requests can be found at the following link: <http://www.uhnm.nhs.uk/aboutus/Statutory-Policies-and-Procedures/Pages/Freedom-of-Information-Disclosure-Log.aspx>

This letter confirms the completion of this request. A log of this request and a copy of this letter will be held by the Trust.

If you have any queries related to the response provided please in the first instance contact my office.

Should you have a complaint about the response or the handling of your request, please also contact my office to request a review of this. If having exhausted the Trust's FOIA complaints process you are still not satisfied, you are entitled to approach the Information Commissioner's Office (ICO) and request an assessment of the manner in which the Trust has managed your request.

The Information Commissioner may be contacted at:

Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF or via www.ico.org.uk.

Yours,



Rachel Montinaro
Data Security and Protection Manager - Records