

Date: Monday, 14th August 2023
Our Ref: MB/CM FOI 5873

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Re: Freedom of Information Request FOI 5873

We are writing in response to your request submitted under the Freedom of Information Act, received in this office on 11th August 2023.

Your request was as follows:

Basic information

On behalf of which organisation and department are you answering this request?

[The Walton Centre NHS Foundation Trust \(WCFT\) - MND Team](#)

Service

Do you offer genetic testing services to people with MND?

Do you offer predictive genetic testing services to at-risk relatives of people with MND?

[Do you offer genetic testing services to people with MND? - Yes](#)

[Do you offer predictive genetic testing services to at-risk relatives of people with MND? - No](#)

Resources for people with MND and family members

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

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

What letters, leaflets or websites do you provide to people having MND genetic testing or predictive testing to facilitate family communication?

[What leaflets and websites do you provide \(or signpost\) to people with MND on genetic testing? - The WCFT use the The MND Association website -
<https://www.mndassociation.org/sites/default/files/2022-11/11%20Inherited%20MND%20and%20genetic%20counselling.pdf>](#)

[What leaflets and websites do you provide \(or signpost\) to at-risk relatives of people with MND on predictive testing? - MND Association website and signpost relatives to their own GP.](#)

What letters, leaflets or websites do you provide to people having MND genetic testing or predictive testing to facilitate family communication? - Nil hand held leaflets, we direct family members to their own GP for specialist referral to a geneticist to access counselling pre-testing.

Resources and training for staff

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

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

What educational resources or training do you have to support staff with MND genetic testing? - No formal training received. But informal discussions occur regularly within the MDT discussing current and relevant updates. For example; the recent criteria change to access genetic screening.

What educational resources or training do you have to support staff with MND predictive testing? - Same as above.

Please see our response above in [blue](#).

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Further information can be found at www.opsi.gov.uk where a sample license terms and fees can be found with guidance on copyright and publishing notes and a Guide to Best Practice and regulated advice and case studies, at www.opsi.gov.uk/advice/psi-regulations/index.htm

If you are dissatisfied with the handling of your request, you have the right to ask for an internal review. Internal review requests should be submitted within two months of the date of receipt of the response to your original letter and should be addressed to the Freedom of Information Office at the address above.

Please remember to quote the reference number, FOI 5873 in any future communications.

If you are not content with the outcome of the internal review, you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted by:

Post: Information Commissioners Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF.

Online: <https://ico.org.uk/make-a-complaint/foi-and-eir-complaints/>

Telephone: 0303 123 1113

Yours sincerely

Mike Burns

Mr. Mike Burns, Executive Lead for Freedom of Information

