



**Patient Factsheet:
What is the UKMH Registry?**

**Patient/Relative Helpline No
0113 206 5270 (during office hours)**

This factsheet has been put together by the MH Investigation Unit at the University of Leeds, to give information for patients and relatives on the UK MH Registry

What is Malignant Hyperthermia (MH)?

Malignant hyperthermia (MH) is a rare, potentially fatal reaction to commonly used anaesthetic drugs. People at risk of MH usually are not aware of their risk, which is caused by a genetic defect.

The UKMH Registry

The purpose of the UKMH Registry is to help people who may be at risk of developing MH to have safe anaesthesia. This is achieved by:-

1. Providing relevant clinical information to patients and healthcare professionals looking after them;
2. Enabling research studies into MH.

Until recently, the only way of testing for MH was for a patient possibly at risk to have muscle biopsy testing at a specialised MH testing centre. The only specialised MH testing centre in the United Kingdom has been based in Leeds since 1970. This enabled the Leeds MH investigation unit to collect information on all patients and families in which MH was present, which then formed the basis of a patient registry. Doctors in the Leeds MH unit have used the patient registry to provide advice and vital information to patients and doctors looking after them.

With the availability of DNA screening for members of some MH families, not all patients testing positive for MH need to come to the Leeds unit. This means that their information has not been added to the patient registry. The specialist MH consultants in Leeds are unable to advise those patients and doctors looking after them about the safest anaesthetic for them or members of their family.

The UKMH Registry has been established, with funding from an endowment from the British Malignant Hyperthermia Association. The new UKMH Registry enables people with MH or from families with MH to join a single UKMH patient registry even if they have not attended the MH diagnostic unit in Leeds.

Who can register for the UKMH Registry?

Anyone who has been diagnosed with MH in the UK, or belongs to a family where MH has been diagnosed. If you have been told by a doctor that you might have MH but the diagnosis has not been confirmed you should ask your GP to make a referral to the Leeds MH unit.

Why register?

By signing up to the UK MH registry, any doctor looking after you can obtain specialist advice about the implications of malignant hyperthermia susceptibility for your planned treatment.

You will also increase the chances of doctors looking after your relatives of being able to receive the most accurate information about your relatives' risk of MH.

A further benefit is that you may be contacted to take part in MH research. Although taking part in research may not be of immediate benefit to you, it may help other people in the future including members of your family.

Do I have to register?

No, it is not mandatory to register but if you do have MH (or are at potential risk of having MH) we hope you will register for the reasons outlined above.

Do I have to take part in research?

No, if you are contacted about a research study you are free to choose whether you participate in the research study or not. Whatever you decide, it will not affect the quality of health care information that we may provide in the future to you or doctors looking after you.

How do I sign up for the registry?

If you would like to be part of the UK MH registry you can do it online using [this link](#). Alternatively you can sign up by phoning us. Click here to find our [contact details](#).

What will I have to do to sign up for the registry?

Signing up to the registry is very straight-forward and involves giving some basic,

personal information about yourself (name, date of birth, GP details, contact details)

If you have been diagnosed to be at risk of MH you will need to tell us when (approximately) and where this diagnosis was made.

If you are joining the register because a family member has been diagnosed with MH you will be asked also to give their name and date of birth.

Who will have access to my personal details?

Data in the UKMH registry will be held securely on a University of Leeds server and will be handled in accordance with the data protection act 1998.

Only NHS staff of the UKMH registry based in the Leeds malignant hyperthermia unit will have access to your personal information.

Researchers engaged in research projects approved by the UKMH registry will have access to information with names, dates of birth and other personal identifying data removed unless you have given specific consent for the use of your personal details in research.

You can sign up to the [UKMH Registry here](#).

If you have any questions regarding the UKMH Registry please [contact us here](#).