

MTM Registry Consent

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Myotubular and Centronuclear Myopathy (MTM and CNM) Patient Registry:
information for patients aged 16-18 years old

Principal Investigator/Data Controller: Professor Hanns Lochmüller, Institute of Genetic Medicine, Newcastle University

You are being invited to join a registry (research database) so that we can learn more about myotubular and centronuclear myopathy. Before you decide if you want to join in, it is important to understand why the project is being done and what it will mean for you. Please read this information carefully and talk about it with your family and friends. There is a glossary at the end of this information sheet to help explain what some of the words mean.

If you have any questions after reading this information, please talk to your parents or guardians, to your doctor, or contact the Registry Curator, Jo Bullivant, at mtmcmregistry@treat-nmd.eu.

You can also use the link above to download or print a copy of this information to keep.

1. Why are we doing this research?

We are interested in people like you with *myotubular and centronuclear myopathy*. We want to learn more about the disease and maybe help make new treatments. To help do this we want to set up a registry (*database*) made up of information about people like you. To make this registry we want to ask if it is OK with you to store information about you on a computer. If you are happy to be involved in this, please talk to your parents and ask them to complete the consent statements on this page so that we can collect and keep your information.

If new treatments are made that may help you, we can then contact you to see if you want to try them (in a '*clinical trial*'). You do not have to be involved in any *clinical trials* and we would talk to you again at a different time if this was a possibility. You and your parents would need to sign a different *consent form* at that time as well.

2. Do I have to take part?

You do not have to take part in this project. Deciding not to take part will not change how we look after you. If you do want to take part then you and your parents will need to agree to the consent statements on this page, to say that you have read this information and that we can keep information about you. You can also download or print a copy of this information to keep, using the link at the top of the page.

If you change your mind and decide you don't want to be part of this project anymore then we will remove the information about you from the registry. Again, this will not change the way we look after you.

3. What will happen to me if I take part?

If you are happy to be part of this project then we will collect information about you from you, your parents, and sometimes your hospital notes. You will not be asked to have any extra tests done for this project. You will not need any time off school other than to come to your usual clinic appointments.

When you have completed this consent page, you or your parents can answer the online questionnaire to enter your information on to the registry. It is stored on a secure computer that is protected by passwords.

4. Will this project help me?

The project may not help you specifically, but the information we collect should help us learn more about *myotubular and centronuclear myopathy* and help develop new treatments in the future.

5. What if something goes wrong with the project?

We do not think that anything will go wrong. The only people who can see the information about you are members of Professor Lochmüller's team who help with the project. The *database* is secure and *password protected* and is looked after by Newcastle University.

6. Will anyone else know I'm doing this?

Only people allowed by Professor Lochmüller will be able to see the information about you. Your parents will also need to know, as they will need to complete the consent statements on this page.

Some people from *research companies* may ask us for information about you if they think they have a treatment that may help you. Any information we provide to them would be anonymous. If Professor Lochmüller thinks that a treatment may be of help to you, we will write to you to ask if you would like to take part in the research. This would be your decision.

7. Who decided the project could be done?

Before any *research* can be done it has to be checked by an *Ethics Committee* (*ours is NRES Committee North East- Newcastle and North Tyneside 1*). This is to make sure that the *research* is a good idea and is safe to do.

This project is organised by the *TREAT-NMD Neuromuscular Network* at Newcastle University and the *Myotubular Trust*. The database will be looked after by Newcastle University.

8. Contact Details:

If you would like to talk to someone about taking part, you or your parents can contact the Registry Curator Jo Bullivant by emailing mtmcmregistry@treat-nmd.eu.

Or you may contact the Patient Advice and Liaison Service (PALS) 0800 0320202.

GLOSSARY –What do these words mean?

Anonymous information – information which does not contain any names or contact details

Clinical trial – an experiment involving patients with a particular disease

Consent – giving permission for something, or agreeing it can be done

Database – a collection of information

Ethics Committee – a group of people who look carefully at research projects to make sure they are properly carried out

Password protected – a way of stopping people from looking at your information

Research – careful investigation of a particular subject

Research companies – a business that pays for investigation of a particular subject

Thank you for reading this information