

## 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: Dr Chiara Marini Bettolo, 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](mailto: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 it would be up to you to decide if you wanted to take part. 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 registry. Deciding not to take part will not change how your doctor looks 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 registry anymore then we will remove the information about you from the registry. Again, this will not change the way your doctor looks after you.

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

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

When you and your parents have completed this consent page, you 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 registry 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 registry?**

We do not think that anything will go wrong. Only people allowed by Dr Marini Bettolo will be able to see the information about you. 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 Dr Marini Bettolo 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 Dr Marini Bettolo thinks that a treatment may be of help to you, we will write to you to tell you about it, so that you can find out more if you want. 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 registry is organised by Newcastle University and the *Myotubular Trust*, and is part of the TREAT-NMD Neuromuscular Network. The database is 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](mailto:mtmcmregistry@treat-nmd.eu).

Or if you live in the UK 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**