

MTM Registry Consent – under 11

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Myotubular and Centronuclear Myopathy (MTM and CNM) Patient Registry: information for patients under the age of 11 years old.

We are asking if you would like to be part of a database called the Myotubular and Centronuclear Myopathy Patient Registry. This information sheet tells you what will happen if you agree to take part.

The decision part is up to you.

Please ask any questions that you have about the registry.

What is a registry?

A registry is a database about people with a specific disease. We want to collect information about people like you who have myotubular or centronuclear myopathy, so that researchers can easily find people with the same illness to take part in their research and find out answers to the questions.

Why have I been asked to take part?

You have myotubular or centronuclear myopathy and your doctor and parents or guardians will have explained what that means. Simply, it is an illness that very few people get and it affects your muscles and can make you very tired. Your body is like a train engine, but the train cannot go very fast because the train track needs to be repaired.

What will happen to me if I take part in the registry?

If you are happy to join the registry then your parents will need to agree to the consent statements on this page, and then fill in some forms

online. Your parents might also speak to your doctors so they can tell us the results of any tests you might have had in the past.

You will not be asked to have any extra medical tests done. You will not need any time off school other than to come to your usual appointments.

You will be looked after in the same way even if you decide not to take part.

Do I have to take part?

You do not have to join the registry and if at any time you don't want to have your details on the registry, just tell your parents. They will not be cross with you and you will be looked after in the same way.

Will joining help me?

We cannot promise the study will help you but the information we get might help treat other children with myotubular or centronuclear myopathy with better medicines in the future.

What if new information becomes available?

Sometimes during research, new things are found out about the research topic. Your doctor will tell you about this if it happens.

Will anyone else know I'm doing this?

We will keep information about you private. This means we will only tell those who need to know that you are taking part in the registry.

Only people allowed by Professor Lochmüller will be able to see the information about you.

Did anyone check this study is OK to do?

Yes. Before any research is allowed to happen, it has to be checked by a group of experts called a Research Ethics Committee. They make sure that the research is fair and done properly.

Who do I contact if I have any questions or need further information?

If you have any questions or do not understand any of the words used, please talk to your parents or guardians, to your doctor, or ask the Registry Curator. The Registry Curator is called Jo Bullivant and you can email her at mtmcmregistry@treat-nmd.eu.



Thank you for reading this – please ask any questions if you need to.