UK Myotonic Dystrophy Patient Registry

Patient information sheet for children aged 6-10 years old.

We are asking if you would like to have your information included in a computer database called the UK Myotonic Dystrophy Patient Registry. By sharing details about how you feel and asking your doctor to add some medical information and test results, scientists will be able to learn more and do more work to help children and adults living with Myotonic Dystrophy. This information sheet tells you what will happen if you agree to take part.

The decision part is up to you.

Please ask your parents / guardians / carers any questions that you have about the study.

Why is it important to share your information?

Sharing your information means that it is easier for scientists and doctors that are working on ways to help children and adults with Myotonic Dystrophy to answer their questions. By joining in with this project, you will be helping others with the condition and adding your own thoughts and feelings to the collection of information we look after.

Why have I been asked to take part?

You have a condition called **Myotonic Dystrophy** and your doctor will have explained what that means. If you or your parents/guardians are unsure about anything the doctors told you, there are patient support groups that can help explain all the details (see the registry website for links) and connect you with other children and families who have the same condition.

Put simply, this is a something you were born with, that not many people have. We are asking children and grown-ups who have this condition to tell us a bit about themselves so we can know as much as possible about how it affects you. This will help the doctors learn more about the best way to help you stay as healthy as possible.

What will happen if I take part in the registry?

If you are happy to share your information then we will ask your parent or guardian to answer some questions about how you are doing and if you are taking any medicine. We will also ask your hospital doctor to share some information when they see you .

You will not be asked to have any extra medical tests done, and you will not need any extra time off school. Your doctors will still look after you in the same way even if you decide not to take part.

If you choose to take part, you and will be asked to type your initials into a form on a computer to say that you understand and are happy to join in. This is called 'giving consent'. After this, you won't need to do anything else! Your parents or guardians will do the rest until you turn 16 then you can add your information yourself if you want.

Do I have to take part?

No, you do not have to take part in the registry. If at any time you don't want to share your information anymore, just tell your parents/guardians, carer, doctor or nurse, and they can tell the people in charge of the registry. Your doctors will still look after you in the same way.

Will joining help me?

We hope that the information you give will be helpful for everyone living with Myotonic Dystrophy in the future, because the more we know, the more the doctors can learn how to help. Medicines to help the condition may take a long time to be discovered and nobody knows when they will be found, so we cannot promise that anyone will receive them. But, the information gathered along the way helps to show that there are children living with Myotonic Dystrophy in the UK, and can encourage and support people to try and find medicines.

Will anyone else know I'm doing this?

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

Only the people who help add your details (like your doctor and your parents/guardians), and people allowed by the doctor in charge of the registry will know you are taking part and will be able to see the information about you. You can tell anyone you like, but you don't have to.

Did anyone check this project is OK to do?

Before any information is collected or any research is allowed to happen, the project had to be checked by a group of experts called a Research Ethics Committee. They make sure that the registry is fair and set up properly, and they are happy that this research is safe and fair. They check everything again every 3 years to make sure.

There is another group of experts called the Steering Committee who carefully check how the information collected by the registry is used and make sure we only share information with people who are trying to help.

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

There is a list of words and what they mean on the next page (a 'glossary').

Please ask your parents/guardians if you need help to understand anything in this leaflet, they are welcome to contact the registry team if they would like our help with anything.

GLOSSARY – What do these words mean?

Clinical trial – a research project to test a possible new treatment, medicine, or therapy with patients living with a particular condition.

Consent – Saying yes to something, or agreeing it can be done. You can always change your mind after giving consent.

Database – a collection of information stored safely on a computer.

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

Registry – a special kind of database for collecting health information.

Research – careful investigation of a particular subject, learning more about something.

Steering Committee – a group of experts, including people from patient groups, who make sure the data collected is only shared with people or companies who are trying to help.

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

UK MYOTONIC DYSTROPHY PATIENT REGISTRY