



# Global Registry for COL6-related dystrophies

## ***Patient information sheet for children aged under 11 years***

We are asking if you would like to join the Global Registry for COL6-related dystrophies, which is a special type of research project ran by Newcastle University in the UK. 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 study.

### **What is research?**

Research is a way we try to find out answers to questions. We want to collect information about people like you who have a condition called “muscular dystrophy” so that the researchers can easily find people with the same illness to take part in their research and find out answers to the questions. Your illness is due to a fault in one of the Collagen 6 genes, so you have what’s called a Collagen 6- related dystrophy (your doctor may also have given you a specific diagnosis of UCMD or Bethlem myopathy).

### **Why have I been asked to take part?**

You have a Collagen 6-related condition and your doctor and parents/guardians will have explained what that means. Explained simply, it is an illness that very few people get and it affects your muscles and joints.

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

If you are happy to be part of project then we will ask your parents and doctor to answer some questions about you.

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 in the research study.



## **Do I have to take part?**

You do not have to take part in the project and if at any time you don't want to take part anymore, just tell your parents or doctor. 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 Collagen 6-related conditions 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. Only you, your parent/guardian and the doctor nominated by your parent/guardian will know you are taking part in the project.

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

### **Did anyone check this study is OK to do?**

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?**

Please ask us or your parents/guardians if you do not understand the research project or do not understand the words used.



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