

Patient Registry for FSHD

Patient information sheet for children aged 6-10 years

We are asking if you would like to join in a research study called the FSHD 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 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 FSHD 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.

Why have I been asked to take part?

You have FSHD and your doctor and parents/guardians will have explained what that means. Simply, it is an illness that very few people get and it affects your face, shoulders, arms and legs. 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 be part of this research study then we will collect information about you from your hospital notes. We would like to put information about you and your illness on the FSHD Registry.

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 research study and if at any time you don't want to do the research anymore, just tell your parents, doctor or nurse. 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 FSHD 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 you are taking part in the research study.

The doctors and nurses at the hospital who look after you will know you are part of this project, but only people allowed by Professor Lochmüller 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.