

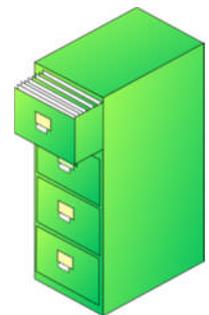
INFORMATION SHEET FOR CHILDREN (6-10 YEARS)

Chief Investigator: Professor Francesco Muntoni

Recording information on the management of your Spinal Muscular Atrophy in the UK
– SMA REACH UK Database in association with the Neuromuscular Clinical UK Network

Please go through this leaflet with your parent or guardian.

You are being invited to take part in a research project as you have Spinal Muscular Atrophy. Research is a way we try to find out the answers to questions. Before you decide whether you want to take part, it is important to understand why the research is being done and what it will involve.



What is it about?

We would like to collect and record information which will help us to improve the care for all children with SMA in the UK. We would like to look at how SMA changes over time and keep a record in a database.

A database is like a filing cabinet where we can keep a lot of information all in one place. The database is called the SMA REACH UK Database. All children with SMA who attend clinics at Great Ormond Street Hospital in London and in Newcastle will also be invited to take part.

Do I have to take part?

No, it is up to you to decide if you want take part. We will still look after you even if you say no.

What will I be asked to do if I take part?

You and your parents will fill out some forms to say you want to take part. You will be asked to come to hospital every 6 months as you do for your normal clinic appointments.

The only difference is that when you come to physio, it may take a little longer than usual as we will be doing a few more things and we would like to video you and take some photos. You can still be put on the database if you do not want



can do it properly.

to be videoed or have your photo taken. These videos and photos will be used to teach other physios how to do your assessment and to test that they



We would like to collect and save information each time you are seen in clinic. The project will last for 2 years. You and your parents/carer may also be invited to one or two group meetings to talk about your SMA assessments if you would like to.

Will joining in with this help me?

It may not help you but may help improve the care of children with SMA in the future.



Will my medical details be kept private if I take part? Will anyone else know I'm doing this?

We will only tell the people who need to know like the doctors taking care of you. We will only put information on the database or share it once your name and address has been removed.

How can I find out more?

You can talk to your parents about the project and ask them any questions that you have. If they don't know the answer you can ask your doctor, or your parents can ask your doctor for you.

