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The University Of Sheffield.

Clinical Trials Research Unit.

HydroDMD

Participant Information Sheet for Children (7-10)

To be shown and read by parent/carer if required

HydroDMD

Study title: Hydrotherapy vs land based therapy **for Duchenne muscular dystrophy**

1. What is research? Why is this project being done?

Research is to find out new things. This research is to see if hydrotherapy (exercises in water) help boys like you who have Duchenne.

2. Why me?

We have asked you because you have Duchenne.

3. Do I have to take part?

No. If you do not want to you do not have to.

4. What will happen?

If you say you will do it, you will be asked to do the same tests as when you go to clinic, like seeing how tall and heavy you are, how well you can blow and how fast you stand up, walk and get up and down stairs. We will ask you to walk up and down a corridor for six minutes. You will do these tests again after a month. Your physiotherapist will then say if you can do it. If so, you may be in a group that gets hydrotherapy or you may not.

You will still do your normal exercises. We may ask you to do the special exercises in a warm swimming pool. After being in the pool we will ask you how tired you are, if it hurt and to wee in a pot. This will go on every week for six months. At the end you will do the same tests. We will ask if you would like to tell us what you felt about doing all this. We will let your usual doctor (GP) know you are taking part.

5. Will joining in help me?

No. It is unlikely to help.

6. What else might happen?

We do not think there will be anything else that happens. Your name and address will be given to researchers if you are interested in taking part in the interview and some of these forms (which include your) name will be sent by post to them.

7. What happens when the research stops?

We will look to see if hydrotherapy is better than the other exercises you do. You may not be able to have more hydrotherapy afterwards.

8. What if something goes wrong?

We do not think anything will go wrong. If something goes wrong your mum, dad or carer will talk to someone who will be able to tell him or her what he or she needs to do about it.

9. What if I do not want to do the research anymore?

If at any time you do not want to carry on, just tell your teacher or your mum or dad. We will not be cross with you.

10. What if I wish to complain about the study?

If there is anything wrong, you or your mum, dad or carer can talk to the doctor in charge of the study.

11. Will anyone else know I am doing this?

No. While the doctors who look after you will know you are taking part, no one else will need to.

12. What happens to what the researchers find out?

Everything is stored in a safe place and only the people doing the research can look at it. This will help show if hydrotherapy is helpful to boys like you who have Duchenne. Your parent/guardian can ask to see the results.

13. Did anyone else check the study is OK to do?

We have checked to make sure it is all right.

Before any research is allowed to happen it has to be checked by a group of people called an Ethics Committee. They make sure the research is OK to do. Your project has been checked by the Cambridge South Research Ethics Committee.

14. How can I find out more about this study?

Your mum, dad or other grown up you trust may be able to answer your questions.

Thank you for taking the time to read this – please ask any questions if you need to.