



## Strength Training for Adolescents with cerebral palsy

### **PARTICIPANT INFORMATION SHEET FOR YOUNG PEOPLE (10-15 years)**

My name is Jennifer Ryan and I am a physiotherapist and researcher from Brunel University London. I am trying to find out if resistance training, a.k.a strength training, can make movements such as walking easier for young people with cerebral palsy. Before you decide if you want to take part, it's important to understand why the research is being done and what it will involve for you. So please consider this leaflet carefully. Talk to your family, friends, physiotherapist or anyone else if you want to.

**Part 1** of this leaflet tells you the purpose of this study and what will happen to you if you take part.

**Part 2** gives you more detailed information about the conduct of the study.

### **Part 1 – Overview of the Study**

#### **Why is this project being done?**

We want to try and answer a number of questions:

1. Do teenagers with cerebral palsy find a resistance training programme acceptable? Does it fit well into day-to-day life?
2. Does resistance training make walking easier, reducing the effort required? Does it increase teenagers' physical activity levels and help them participate more fully in everyday life?
3. How does resistance training improve walking? What effects does it have on the different muscles and tendons in the leg?

#### **What is resistance training?**

Resistance training, or strength training, is designed to make muscles stronger. When you lift a weight over and over again your muscles will gradually become stronger. It has been shown that people with cerebral palsy have weak calf muscles, which may make it more difficult for them to carry out activities such as walking, running or standing up from a seat. In this study we are aiming to strengthen the calf muscles as we think this will result in the most improvements in walking.

#### **Why have I been chosen?**

You have been chosen because you are a teenager with cerebral palsy. You will help us to improve the physiotherapy we give to teenagers with cerebral palsy in order to make it easier for them to walk. We are asking 60 teenagers all together.

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

No. It is up to you. You can change your mind at any time during the study. If you don't want to take part, just say no! If you don't want to tell us yourself, you can ask your mum, dad or carer to tell us that you don't want to take part. If you decide you don't want to take part the care you receive, either now or at any time in the future, will not be affected. If you agree to take part, we will ask your parent or guardian to provide consent by signing two forms.

### **What will happen during testing?**

We will ask you to come to Brunel University, London three times to take part in a number of assessments. After you come the first time you will be randomly chosen to take part in a resistance training programme or to continue with your usual physiotherapy (we understand that at the moment you might not be doing any physiotherapy). We use a computer to randomly decide whether you receive resistance training or not and we do not have a say in this. It is really important that even if you do not do the resistance training that you come back to Brunel University, London for the assessments. Otherwise we won't know if resistance training is any better than usual physiotherapy.

In order to find out if resistance training makes walking easier and increases participation in physical activity, and what effect it has on muscles and tendons we will do the following assessments in Brunel University London:

- 1. Taking body measurements** (height, weight and leg length)
- 2. Walking on a treadmill** while we record how you move using motion cameras (like in Lord of the Rings!)
- 3. We will measure how much energy you use while you sit down for 10 minutes and while you walk around a room for 6 minutes.**
- 4. We will ask you to complete 5 questionnaires.** Two questionnaires will help us to see how active you are in everyday life. Once we know this we can see if resistance training changes the amount of activity you can perform in everyday life. Two questionnaires will ask about your general health (e.g. how you are feeling today, if you have any pain) and one will ask about how much you've seen your doctor, physiotherapist and other health professionals in the past 3 months.



**We measure your movement**

Available online at: <http://ccorner.duke4.net/the-idea-of-capturing-motion/>

5. We will measure your **calf muscle strength**. To do this we will ask you to sit on a special chair called a dynamometer. One foot will be strapped onto a foot plate connected to a machine. The machine will **slowly move your foot backwards and forwards**. This will feel like your muscles are being fully stretched but should not cause any pain.

6. While your foot is moving we will take **pictures of the muscles inside your leg**. To do this we will rub a little gel over your lower leg that allows us to take pictures of your muscles with an ultrasound machine. The gel may be cold but it will not cause any pain. You do not have to do anything. We will ask you to keep your leg relaxed during the testing and not to squeeze your muscles.



The machine that measures how much energy you use



A dynamometer



We take pictures of your muscles

7. We will **measure if your ability to walk, run, jump and stand** has improved by asking you to do a number of activities like running and jumping. We will videotape you doing this and will measure how good your quality of movement is from the video. You will be asked if you are happy to have a photograph or video taken before you take part. If you don't want to have a photograph or video taken we won't take one and you can still take part in the study. We will also time you walking over 10 m.

8. Before you leave we will ask you to take home an **activity monitor to wear for 7 days**. This is a small device that you wear around your waist. We will ask your mum, dad or carer to post this back to us after you've worn it.



Activity monitor

Sometimes we take photographs and videos during the assessment to use for conferences and educational purposes. If we take a video or a photograph we will make

sure your face is blurred before using it so that no one can recognise you. You will be asked if you are happy to have a photograph or video taken before you take part. If you don't want to have a photograph or video taken we won't take one and you can still take part in the study.

## Resistance Training Programme

If you are randomly assigned to the resistance training programme you will be asked to:

**1. Do exercises 3 times a week for 10 weeks.** You will do exercises once a week for an hour in your local gym with a group of other teenagers taking part in the study. You will do exercises on two other days a week (for about 20 minutes) in your home. Participation in this study will involve the completion of an exercise diary twice a week recording your exercise – this should not take in excess of 5 minutes per entry.

**2. Your physiotherapist will give you exercises for your calf muscles.** The exercises you do will depend on what you're able to do at the start of the programme and will be changed as you get stronger. Examples of exercises include an exercise with Theraband, going up and down on your toes, going up and down on your toes with a weight added to your shoulders to make it harder, and pointing your toes against a weights machine.



Exercise with Theraband

**3. We will ask you to take part in an interview** with a researcher when you finish the programme. During the interview you will be asked if you liked the programme, if you found it difficult to do and any other thoughts you have about it. You can ask your mum, dad or carer to take part in the interview with you if you want. This interview will be recorded and we may use quotes from you when we write up the study. However we will use a made up name so that no one knows the quotes are from you.



Going up and down on your toes



Pointing your toes against a weights machine

4. A researcher will also **visit you at home and in the class** four times to see how well you are doing the exercises.

*In exchange for your time and effort we will be offering a £20 Love2shop voucher on completion of the study. All teenagers who take part in the study will receive a voucher at their final assessment.*

### **What are the benefits and problems with taking part?**

The benefits you might get from the study are to increase your muscle strength. The information we get might also help physiotherapists to provide better treatment to children with cerebral palsy in the future.

The problems could be that your muscles may be sore after the assessments and/or after you do the exercises. This is completely normal and is a sign that your muscles are working hard. However if you think find that it is too painful you can withdraw from the study.

We use sticky tape to attach sensors to your legs and feet to record your movement, video your muscles and measure how much your muscles are working. This can be painful when we remove it (like taking off a plaster). We will do our best to make it hurt as little as possible.

---

## **Part 2 – Further Information**

This section details the organisation of the study and complaint procedures if you are not happy with the conduct of the study.

### **What happens when the research study stops?**

We will collect all the information together. This includes bringing information collected while you do the programme in your physiotherapy department or gym to Brunel University London. None of this information will include your name. We will then decide if resistance training might be useful for changing how teenagers with cerebral palsy's muscles work, if it improves their walking and everyday activity, and if teenagers find it easy to do.

### **What if something goes wrong?**

If you have any concerns you can tell your mum, dad or guardian who will be able to talk to someone who will tell them what they need to do about it. If you don't want to talk to a parent or guardian you can talk to your physiotherapist who will know what to do about it.

### **What if I don't want to do the research anymore?**

Just tell your mum, dad, guardian, physiotherapist, or any of the researchers at any time. They will not be cross with you. You will still have the same care from your physiotherapist.

### **Will anyone else know I'm doing this?**

The people in our research team will know you are taking part. Your physiotherapist will also know you're taking part. No one else will know because we will not use your name or address. You will be given a study number which will be used to identify you instead.

The only exception to this is if you tell us something during the interview that suggests that you or others are being placed at risk of significant harm. In this case we are obliged to pass this information on to the manager of the therapy team involved. We will talk to your parents and you about what will happen before we tell the manager this information.

### **What happens to what the researchers find out?**

When we collect your information we will make sure it is stored in a safe place and only the people doing the research study can look at it. We will show physiotherapists and doctors the information by putting it in medical journals and presenting it at conferences. A short summary will also be on the study's website. No-one will know you were in the study.

### **Did anyone else check the study is OK to do?**

This study has been checked by several people, to make sure it is alright including the ethics committee for your physiotherapy department and Brunel University London's ethics committee. An ethics committee is a group of people who decide if it is ok to conduct a research study. If you have any concerns or complaints about the conduct of the researchers or the study you or your parent can contact Professor Christina Victor (Chair of the Research Ethics Committee, College of Health and Life Sciences) [christina.victor@brunel.ac.uk](mailto:christina.victor@brunel.ac.uk). You or your parent can also contact your local Patient Advice and Liaison Service (PALS) on X

### **How can I find out more about this study?**

Your mum, dad, carer or other adult you trust may be able to answer your questions or you can contact the researchers to ask any questions. Your physiotherapist can also help you find out more about the study.

**Contact for further information:** You can get more information or answers to your questions about the study, your participation in the study, and your rights from a member of the STAR trial who can be telephoned or texted at [0785 4066001](tel:07854066001) or emailed at [Starstudy@brunel.ac.uk](mailto:Starstudy@brunel.ac.uk).

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