

## Children's Participant Information Sheet (Older Child)

Study title: **The Australasian Cerebral Palsy Musculoskeletal Health Network Study**

Locality: New Zealand Ethics committee ref.: 2025 FULL 21456

Lead investigator: Professor Susan Stott Contact phone number: 0212242298

### Why am I being asked to join the study?

- You have cerebral palsy and you sometimes or always use a wheelchair to move around.
- Children with cerebral palsy may go onto have problems with their hips, spine and bones (known as the skeleton).

### What is the study about?

- New Zealand team is working with 3 other Children's hospitals in Australia for this study.
- We want collect information about you and your health. We to see if this information may help us understand if there is any treatment that may prevent problems with the skeleton for children in the future.



### What do I need to do in the study?

- You will need to come into the hospital in Auckland once every year for the next 4 years with your mum or dad or caregiver.
- At this appointment, you will have a bone scan called a DEXA\* scan. There is a picture underneath this to show you what it looks like. You will also have a blood test.
- A physiotherapist will measure the movements of your legs, arms and spine. The way you move will be video recorded.
- You will help your mum, dad or caregiver answer questions about your cerebral palsy, school and the fun things you like to do.
- The research nurse will look at your hospital notes to see if there is any new information about your health that is important to the study.

- The visit to the hospital will take about 4 hours to finish, which is a long time. You can have as many breaks in-between so you do not get too tired.



\* Picture of a DEXA scanner

### **What will happen with my information?**

- The information from your hospital visit will be entered onto a database at the Queensland University in Australia, where it is kept safely. Only the research team can see this information.
- We do NOT enter any information about you like your name, birthday, address or hospital number.

**Please let your parent/ caregiver and the researcher know you understand the information and if would like to take part in the study.**

### **Who can I contact to find out more?**

If you, mum or dad or the person taking care of you have any questions, concerns or complaints about the study at any stage, you can contact:

*Janene McMillan* (Liggins Senior Research Nurse ) on Email: [MsK.study@auckland.ac.nz](mailto:MsK.study@auckland.ac.nz)

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

*Phone:* 0800 555 050

*Fax:* 0800 2 SUPPORT (0800 2787 7678)

*Email:* [advocacy@hdc.org.nz](mailto:advocacy@hdc.org.nz)

You can talk to your family/ whānau

Or contact *He Kamaka Waiora (Māori Health Team)* Phone: (09) 486 8324 ext. 2324

You can talk to the health and disability ethics committee (HDEC) that approved this study:

*Phone:* 0800 400 569 (Ministry of Health general enquiries)

*Email:* [hdec@moh.govt.nz](mailto:hdec@moh.govt.nz)