Te Whatu Ora
Health New Zealand

The New Zealand Cerebral Palsy Register
Te Rēhita a Hōkai Nukurangi Aotearoa

Starship Children's Health

Why am I being asked to join the NZ Cerebral Palsy Registry?

Children's Participant Information Sheet
(Ages 7 –11 years)

Study title: **New Zealand Cerebral Palsy Register**

Locality:	New Zealand	Ethics committee ref.:	**13/NTA/130**
Lead investigator:	Professor Susan Stott	Contact phone number:	**0212242298**

Why am I being asked to join the NZ Cerebral Palsy Registry

- Cerebral palsy is a condition that can make moving around difficult. Your doctor and / or whanau have told us you have cerebral palsy.
- The New Zealand Cerebral Palsy Registry is a collection of information on all people in New Zealand with cerebral palsy. It can tell us how many people have cerebral palsy and what things are needed to help people with cerebral palsy.
- Your parent or person who looks after you will read this form with you. They can help to answer questions you have and so can the people listed on p2 of this form.

What information is on the NZ Cerebral Palsy Registry?

- We collect information just about your cerebral palsy. It includes where you were born and health terms used to describe your cerebral palsy, like how you move, talk, and play.
- We find the information from doctor's letters and your parents or family.
- **There are no new measures or tests to be done.**

How do I join the NZ Cerebral Palsy Registry?

- Read this information sheet and talk with your family. The people doing the study will then wait a month before we start to collect information from your records from the hospital.
- Your parents can go online and fill in information https://nz.cpregister.com/ .
- Your parents can decide not to have your information on the Register, and this is absolutely fine, it will not affect the care you receive

How do we look after the information on the NZ Cerebral Palsy Registry?

- The information you provide to the Register is kept safe
- The information is available to the study team and some health workers where you live.
- When you turn 16 years old, we will check you still want your information on the Register.

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:
NZ CP Register team: *Dr Anna Mackey and Alexandra Sorhage*
Starship Children's Health text or phone: **0212242298** or Email: nzcpregister@tewhatuora.govt.nz

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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@advocacy.org.nz*

You can talk to your 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 4 ETHICS
Email: hdecs@health.govt.nz

Thank you