Te Whatu Ora
Health New Zealand

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

Starship Children's Health

Children's Participant Information Sheet
(Ages 12-16 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 have also been given information. They can help to answer questions 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 and what health services related to your cerebral palsy you have seen.
- 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.
- You and your parents can also go online and fill in your information if you would like to: https://nz.cpregister.com/ .

What if I <u>do not</u> want my information on the NZ Cerebral Palsy Registry?

- Ask your parents or person who looks after you to tell us you do not want your information collected by the Registry, by contacting us within 4 weeks of getting this information.

Contact us by: Email: *nzcpregister@tewhatuora.govt.nz* (Include name, date of birth; NHI of the person)

- Telephone: (09)307-4949 ext 21898 (24 hour answer service available)
- Your parents or person who looks after you completes 'Opt-out' form at end of this sheet
- If your parents or person who looks after you decides not to have your information on the Register, this 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 at any stage, you can contact the people collecting the information
NZ CP Register team: *Dr Anna Mackey and Alexandra Sorhage*
Starship Children's Health by texting or phoning: **0212242298** or Email:
nzcpregister@tewhatuora.govt.nz

You can talk to someone not involved with the Register:
Independent health and disability advocate:

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