

Participant Information Sheet			
Study title:	The New Zealand Cerebral Palsy Register		
Locality:	New Zealand	Ethics committee ref.:	13/NTA/130
Lead investigator:	Professor Susan Stott	Contact phone number:	09 373 7599 Ext 82561

What is the NZ Cerebral Palsy Register?

The register is a confidential database of clinical information about all people in New Zealand with Cerebral Palsy (CP). Information collected includes birth details and description of your CP. The NZ CP Register has been set up in collaboration with the Australian CP Register. Every three years we will contribute our de-identified details (that is information with no names) to the Australian Register; allowing us to see how we compare to the rest of the world.

Why is the NZ CP Register needed?

CP is the most common cause of physical disability in childhood. There is no known cure and the rates of CP have remained unchanged despite recent advances in medicine. People with CP can lead fulfilling lives, but having a better understanding on the causes and impact of CP can help improve the current health services and interventions available.

What are the aims and potential benefits of the NZ CP Register?

If everyone in NZ with CP contributes data, we will be able to i) Know how many people have CP in NZ and how this affects them ii) Improve health and education planning in NZ for people with CP iii) Promote research to assess interventions and preventative strategies.

How do I participate in the NZ CP Register?

Participation is voluntary. When you receive this information about the NZ CP Register, we will allow a period of 4 weeks to pass before the Register team or health professional enters health information of the person with CP onto the register. The information needed to complete registration is usually found from medical notes or speaking to health professionals who look after the person with CP. e.g. paediatrician, physiotherapist.

If you do not want to have your information included on the NZ CP Register, it is important that you let us know by contacting us within 4 weeks of receiving this information by:

- Completing the form at the end of this information sheet
- Email: nzcpreqister@adhb.govt.nz (Include name, date of birth; NHI of the person)
- Telephone: (09)307-4949 ext 21898 (24 hour answer service available)
- Download the opt-out form: <https://nz.cpreqister.com/Public/DownloadForms>.
- Ask your health professional to contact the NZCPR on your behalf

You can choose to opt-out of your de-identified information being shared with the Australian CP Register or from being contacted with information on relevant research studies. If you chose to opt-out, you do not have to give a reason and it will not affect the health care you receive. Please feel free to talk about the NZ CP Register with other people, such as family, whanau, friends or healthcare providers.

How do we protect your information?

We respect your privacy. The information you provide to the Register is strictly confidential and data will be stored with utmost security and care.

- The register requires that your personal information is identifiable to NZ CP Register staff and health professionals in your local DHB region.
- The NZ CP Register team checks all the information on the register to ensure it is complete and correct.
- If information is collected on the NZ CP Register before a child's 5th birthday the NZ CP Register team will re-confirm the diagnosis at 5 years of age, through contact with the participant; health professional or medical notes.

- De-identified data is sent to the Australian CP Register for inclusion in their three yearly reports. You will not be able to be identified from any of the shared data. All reports will be made available on the NZCPR website for anyone to read
- Your information **cannot** be freely accessed by 3rd parties. A professional wanting to use or access any of the NZCPR data for research purposes will require NZ Health and Disability Ethics (HDEC) approval; local DHB approval and will be reviewed by the NZ CP Register Governance Committee. For further information on how we work to protect your information please contact the NZ CP Register team
- When a participant on the Register turns 16 years old, we will make all reasonable attempts to contact the parent/ caregiver to determine if future contact should be transferred to the participant

What about deleting an existing record?

Your identifiable information is kept on the NZ CP Register indefinitely. You can ask us to remove your information from the Register at any time: your record will become “silent” and the NHI, date of birth and any information relating to CP on record will be retained for statistical purposes only.

Further information on the NZ CP Register:

- The Register is being led by Professor Susan Stott, Paediatric Orthopaedic Surgeon, Starship Children’s Health, Auckland, in conjunction with a team of health professionals and stakeholders from across New Zealand
- The Register is currently being sponsored by Starship Foundation, NZ, with contributions from Cerebral Palsy Society of NZ and Allergan Ltd, Australia.
- This proposal has received ethical approval from the NZ Health and Disability Ethics Committee, ethics reference number (13/NTA/130).
- It is highly unlikely you could be injured participating in this proposal; if you were you would be able to apply for compensation from ACC.
- The Register is planned to continue indefinitely. Should funding for the NZCPR cease, all data held by the Register will be maintained securely by the Australian CP Register.

Who to contact for more information or if I have concerns?

NZ CP Register team: *Dr Anna Mackey; Alexandra Sorhage* Starship Children’s Health on Tel: 09 307 4949 Ext 21898 or Email: nzcprregister@adhb.govt.nz

If you want to talk to someone who is not 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

If you require Māori cultural support please talk to your whānau in the first instance.
 Alternatively contact He Kamaka Waioira (Māori Health Team) Phone: (09) 486 8324 ext 2324

If you have any questions or complaints about the study you may contact the: *Auckland & Waitematā District Health Boards Maori Research Committee or Maori Research Advisor* Phone 09 4868920 ext 3204
 You can also contact the health and disability ethics committee (HDEC) that approved this study on: Phone: 0800 4 ETHICS Email: hdecs@moh.govt.nz

OPT-OUT FORM New Zealand Cerebral Palsy Register (NZCPR)
(Please tick relevant option if you DO NOT wish to participate)

- I would like to opt-out of having my / my child’s information entered onto the NZCPR
- I do not agree to have my de-identified data shared with the Australian CP Register group
- I do not wish to be contacted about taking part in relevant research studies
- I would like to remove an existing record from the NZCPR.

Signature: _____ Date: ____/____/____

Name of person with Cerebral Palsy: _____ NHI: _____

Post: NZCPR; C/o Paediatric Orthopaedics, Starship Children’s Health, Private Bag 92024, Akld 1142; or Scan and email the form to: nzcprregister@adhb.govt.nz