

Parent / Guardian 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 3074949 Ext 21898

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 child's 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. 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 benefits of the NZ CP Register?

A register has the potential to i) Know how many people have CP in NZ and how this affects them ii) Improve health 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.

We only collect information that is relevant to CP. This includes birth history (place of birth, birth weight, gestational age, any relevant investigations or time spent in a special care unit); type of CP (including time of diagnosis and related health services involved at that time) and functional abilities (classification scores for movement, eating and communication, and information relating to vision, speech, epilepsy, intellect). This is a one-off data collection. We do not go back into your medical records once registration is complete. Note: If your child is under 5 years of age when first entered on the Register we reconfirm diagnosis and a functional ability after their 5th birthday, to ensure nothing has changed in early development.

Can I complete a registration for my child?

Yes, you can do this by entering the following address into your web browser <https://nz.cpregister.com/Member/Add>. This will allow you to create a membership login and you can enter all of your data yourself. Once you have a membership login, you can check all of your information and make changes up until the Registration team "Approve" the registration, after 'Approval' you will then need to contact the Register team to make additional changes. You can also download and print a manual form from the website (https://nz.cpregister.com/Public/nzl/SSH_CP_Form.pdf) and send this to the Register team.

If you do not want to have 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: nzcpregister@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.cpregister.com/Public/DownloadForms>.
- Ask your health professional to contact the NZCPR on your behalf

You can choose to opt-out of 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 provided to the Register is strictly confidential and data will be stored with upmost security and care.

- The register requires that the person with CP's 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.
- De-identified data is sent to the Australian CP Register for inclusion in their three yearly reports. A person with CP 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
- 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 removing an existing record?*

Identifiable information is kept on the NZ CP Register indefinitely. You can ask us to remove information from the Register at any time: the record will become "silent", which means we can't view your information; we will not make contact with you to advise you of research projects, we will not use any of your information for reporting purposes. We will keep the information relating to the type of CP only, for statistical purposes.

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.
- This proposal has received ethical approval from the NZ Health and Disability Ethics Committee, ethics reference number (13/NTA/130).
- 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: nzcpregister@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@hdec.org.nz

If you require Māori cultural support please talk to your whānau in the first instance.

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

If you have any questions or complaints about the study you may contact the: *Auckland & Waitemata 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: hdec@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 NZCP (see * information above)

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: nzcpregister@adhb.govt.nz