

What is the CP Register?

The CP Register is a database of clinical information about cerebral palsy (CP). Information collected about each person with CP includes birth details, type and severity of cerebral palsy, other associated impairments and parent demographics. There are CP Registers in each state and territory, as well as an Australian CP Register which consolidates the information and provides a national picture of CP. The Australian CP Register was launched in 2007 and will be one of the largest CP Registers in the world.

People with cerebral palsy and their families are asked to register with their state or territory CP Register.

Why is the CP Register needed?

CP is a disorder of movement and posture resulting from damage to the developing brain. It is the most common cause of physical disability in childhood, with over 600 new cases in Australia each year. There is no known cure and rates have remained unchanged despite many recent advances in medicine. It is now recognised that most CP occurs as a result of factors present prior to birth, however little is known about such factors. For 80% of people, the cause of CP will be unclear.

The CP Register provides a coordinated data collection system for CP in Australia, and will increase the scope of research into CP. It will improve research quality by providing access to a large population sample.

What are the aims of the register?

The main aims of the register are to:

- Monitor trends of CP
- Gain further understanding about the causes of CP
- Develop and evaluate preventative strategies
- Assist in planning services for people who have CP

The Australian CP Register will provide a national framework for research. The information contained on the register will assist with research projects that focus on causes, prevention and management of cerebral palsy. In addition, the register will generate reports on demographics, frequency, distribution and severity for government and service providers. This will enable better planning for the present and future service provision needs of people with cerebral palsy.

How can I participate?

People with CP and their families can register in a number of ways:

- Log in to the CP Register website www.cpreregister-aus.com.au and submit the required information yourself
- Contact your state or territory register directly by phone or email (phone 1300 30 29 20 or see <https://secure.cpreregister-aus.com.au/pubs/ContactUs.aspx> for your local register's contact details)
- Give permission for your health practitioner or education professional to register your details

Children under the age of 5 years will be contacted again after their fifth birthday, for final confirmation of details. Please notify the register if your personal details change.

What about consent and withdrawal of consent?

Registration is voluntary. If you would like to have your details included on the CP Register you will be asked to provide written consent. Your details cannot be included on the register until a signed consent form (paper) is received by your state or territory register. You can download the consent form from <https://secure.cpregister-aus.com.au/pubs/DownloadForms.aspx> or contact your local register and they will send one to you.

There are different levels of consent on the CP Register. You will be asked to consent to:

1. The collection, recording and storage of information on your state or territory register. This may involve consulting birth and current medical records*
2. The transfer of de-identified information to the Australian Cerebral Palsy Register
3. Receiving invitations from register staff to participate in research projects
4. Health professionals that you nominate being contacted to assist in completing and verifying the register information*

You can choose your contribution to the register by selecting your level of consent. You can change your level of consent at any time by submitting a revised consent form to your local register. If, in the future, you change your mind about participating in the register, you can withdraw consent and your name will be removed from the register. This will not disadvantage you in any way or affect services you are receiving.

* Please register even if you do not know the answers to all of the questions on the form. We can help fill in any gaps when we receive your registration. For example, some people will have received a diagnosis prior to the development of the standardised GMFCS and MACS scales used on this form. We can help to identify this information.

What about privacy and confidentiality?

We respect your privacy. The information you provide to the CP Register is strictly confidential and will only be seen by register staff from your state or territory. Only your de-identified data will be included in the Australian CP Register. Any research or reports generated from the register or information provided to other researchers and members of the public will be free of personal identifying information.

If you consent, from time to time CP Register staff may contact you with the option of participating in a research study. Register staff will forward you study information and you can then contact the researchers directly if you would like to participate or if you require more information. It is your decision to agree to or decline these offers. The CP Register will never provide your personal or contact details to researchers or anyone else.

This information sheet is for you to keep. If you have any questions or would like to know more about this project, please contact your local CP Register.

Phone **1300 30 29 20** for contact details, or view them at <https://secure.cpregister-aus.com.au/pubs/ContactUs.aspx>