



Register

Queensland

Queensland Cerebral Palsy Register

Phone: 07 3358 8122

Fax: 07 3358 8143

PO Box 386
Fortitude Valley QLD 4006

cpregister@cplqld.org.au

www.qcpr.org.au

*leading to a
better
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Research into cerebral palsy

Research Updates

If you join the Queensland Cerebral Palsy Register (QCPR) we will send you updates on research into cerebral palsy and details of all the research that the QCPR collaborates in, including new information about possible causes of cerebral palsy from the Australian Cerebral Palsy Register (ACPR).

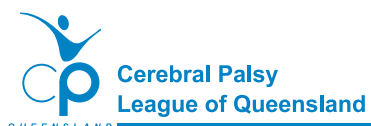
Participation in Research

If you give consent, we will send you details outlining opportunities to participate in research projects in Queensland. We will **never** give your name or address to researchers (or anyone else). If you consent to be contacted for research, the QCPR will write to you directly with information about the project and you can contact the researchers **if you want to** participate.

Consent for Research

You can give consent to be contacted for research when you register, or give consent later. You can also withdraw your consent at any time. We hope many people will take part in research, but the important thing is that it is entirely up to you.

***Research into cerebral palsy is important work and we need
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Can I register?

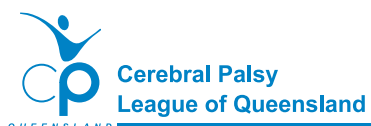
Anyone born or living in Queensland who is thought to have cerebral palsy can register, no matter how old they are.

Even if you are not yet certain of the diagnosis of cerebral palsy, we still encourage you to register. Your record can be amended or deleted if the diagnosis is changed later.

Please Register Now

Please register now, even if you cannot answer all of the questions on the registration form. Staff at the Queensland Cerebral Palsy Register (QCPR) will contact you and, with consent, your treating health professionals, to get all the necessary details.

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How do I register?

Registration is simple, safe and secure. You can register via the Internet or mail.

Online

1. Log-on to the Queensland Cerebral Palsy Register (QCPR) website at: www.qcpr.org.au
2. Click on **Register Now**
3. Click on **Download the PDF Consent Form**. Complete this and send it in to QCPR, PO Box 386, Fortitude Valley, QLD 4006.
4. Click **Back**
5. Click on the **Australian CP Register** website
6. Click on **Sign Up** and complete the secure online registration for online membership and submit a new CP Record. Your postcode will determine which state register your record goes to.

Hard Copy

1. Fill in the **Consent Form** and **Registration Form** in this pack, or
2. Log-on to the QCPR website at: www.qcpr.org.au
3. Click on **Register Now**
4. Click on **Download the PDF Consent Form** and **Download the PDF Registration Form**. Complete both of these forms and send to QCPR, PO Box 386, Fortitude Valley, QLD 4006.

Mail

1. Contact QCPR on **(07) 3358 8122** or email cpregister@cplqld.org.au
2. QCPR will send you the **Consent Form** and **Registration Form** to be completed and sent to QCPR, PO Box 386, Fortitude Valley, QLD 4006 or faxed to QCPR: (07) 3358 8143

If you are unable to register via the Internet or mail please call **(07) 33588122** and we will organise a suitable alternative.

No matter which way you choose to register, your registration will not be activated until your **signed Consent Form** is received by QCPR.

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How secure is my information?

The Queensland Cerebral Palsy Register (QCPR) database is a secure website with 128 bit encrypted access and two fire walls, which makes it more secure than Internet banking.

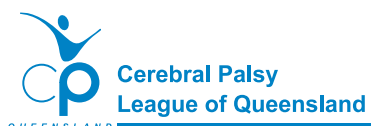
The QCPR uses a highly secure Internet connection (Secure Sockets Layer) to protect against the loss, misuse or alteration of any information we receive from you.

Only you and QCPR staff have access to your information.

You (and/or nominated family members) will always have 24 hour access to your own information via an encrypted password website. No one else will be given the name, address or personal information that you supply to the Register.

Your signed, hard copy (paper) Consent Form will be kept at the QCPR office and this facility will be locked. No one, other than the Register staff, will have access to the Consent Forms.

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Why should I register?

Finding More about the Causes of Cerebral Palsy

Help us to find the causes of cerebral palsy.

In Australia, it is estimated that a person is born with cerebral palsy every 18 hours. As the population increases, so does the number of people born with cerebral palsy. An important method of finding more about the causes of cerebral palsy and preventing it lies in population databases, such as the Queensland Cerebral Palsy Register (QCPR).

Once causes are identified we can work on preventions. The speed we can identify factors depends on your decision to register.

Better Services

It is a fact that no one knows how many people there are with cerebral palsy in Queensland. Therefore, funding allocations are based on guesswork.

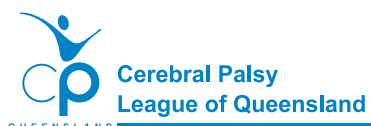
No one has authoritative statistics to convince any service providers where they should focus services or convince governments to fund such services.

The QCPR will provide authoritative statistics and remove a significant obstacle for funding and service provision to people with cerebral palsy, wherever they live.

Better Interventions

It is believed that providing better services to young people with cerebral palsy will improve the quality of their lives in later years. At present, there are no population statistics about how people with cerebral palsy live. The QCPR will measure how people with cerebral palsy live, work and are educated in order to track trends over time. If services improve, or get worse, we will be able to report the impact.

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How is my privacy protected?

Safeguarding your Personal Information

Your privacy and confidentiality is assured. The information you provide to the Register is strictly confidential and will only be seen by Queensland Cerebral Palsy Register (QCPR) staff.

We will **never** provide or sell your information to any other person or agency.

Your name and address will **not** be provided to researchers by the QCPR.

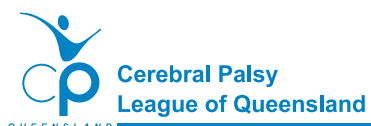
The Australian Cerebral Palsy Register (ACPR) does not seek, and will not hold, personal information. Information will therefore be **de-identified*** before being forwarded, with your consent, to the ACPR.

Access to your Service Records

The QCPR is not part of any other service so it will not have access to hospital or service provider records unless you give your permission.

***De-identified data does not contain information which could identify an individual.**

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What is cerebral palsy?

Cerebral palsy is an “umbrella” term describing a group of chronic conditions affecting body movement, posture and muscle coordination. It is caused by damage to one or more areas of the developing brain.

“Cerebral” refers to the **brain**; “Palsy” refers to weakness/poor control.

No two people with cerebral palsy are the same. Symptoms can range from barely noticeable to severe.

Cerebral palsy is **not progressive**, however, secondary conditions such as muscle tightness, may develop. These secondary conditions can get better, worse or remain the same, over time.

There may also be associated disabilities such as epilepsy or intellectual, visual, hearing and speech impairments.

Cerebral palsy is not a disease or illness. You cannot catch cerebral palsy and it is not hereditary.

There are four (4) main types of cerebral palsy:

Spastic cerebral palsy - tight muscle tone, causing stiff and jerky movements.

Hemiplegia - affects one side of body

Diplegia - affects legs more than arms

Triplegia - affects both legs and one arm

Quadriplegia - affects both legs and both arms

Dyskinetic cerebral palsy - muscle tone fluctuates between floppy and tense causing difficulty with control and coordinated movements. This category includes athetosis and dystonia.

Ataxic cerebral palsy - low muscle tone and poor coordination, causing a shaky appearance or tremors.

Hypotonic cerebral palsy – decreased tone and increased reflexes.

These are only medical terms - it is important to recognise that a child is an individual and his/her needs are special.

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What is the Australian Cerebral Palsy Register?

The Australian Cerebral Palsy Register (ACPR) is a national collection of statistics on cerebral palsy from the states and territories of Australia. The Register collects **de-identified*** information about individuals with cerebral palsy who were born in, or reside in, Australia.

Each state and territory manages their own register or database. If you give consent, we will send **de-identified*** information to ACPR.

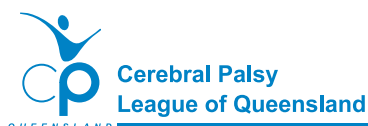
This **de-identified*** information will be used for important research into the factors that influence or cause cerebral palsy.

Since causes of cerebral palsy are usually complicated, it is difficult to identify the important yet common factors.

We all hope that one day we will be able to prevent many people from having cerebral palsy. The ACPR collaboration is one of the major ways by which a greater understanding of the causes and subsequent prevention of cerebral palsy is being sought.

*** De-identified data does not contain information which could identify an individual.**

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What is the Queensland Cerebral Palsy Register?

The Queensland Cerebral Palsy Register (QCPR) is a web-based database of information about people with cerebral palsy who live in Queensland.

Information kept on the Register

The QCPR will be an important source of information for public health and other research including:

- Investigating the causes of cerebral palsy;
- Finding ways to prevent and manage cerebral palsy, and
- Helping in the planning of services for children and adults who have cerebral palsy.

Information collected and kept on the Register includes:

- Contact details, date and place of birth, gender
- Housing details
- Information from pregnancy and birth. This will include information about birth parents such as name, occupation and number of previous pregnancies
- Classification of cerebral palsy including type and severity both initially and at 5 years
- Timing and cause of cerebral palsy (if known)
- Any associated disabilities such as epilepsy, intellectual, visual, hearing or speech impairments
- Health professionals presently involved with providing services to the person with cerebral palsy

From this information, we will be able to produce reports about people in Queensland with cerebral palsy. These reports will describe large groups of people with cerebral palsy only, so there is no possibility of you or any other individual being identified.

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Do I have to give consent?

Participation in the Queensland Cerebral Palsy Register (QCPR) is voluntary.

The Register has “Opt on” consent. This means you have to give consent to go on the Register. No details can be entered before you give permission.

There are different levels of consent for you to participate in the QCPR.

- The collection, recording and storage of information on the QCPR – *This is the basic register*
- Transfer of information to Australian Cerebral Palsy Register (ACPR) – *See ACPR Factsheet*
- Receiving invitations from Register staff to participate in research studies – *See Research Factsheet*
- Nominated Health Professionals can be contacted to assist completing and verifying information – *Allows QCPR staff to contact service providers for any missing information*
- Information from Queensland Health medical records to complete registration – *Not included in kit. If required, call (07) 3358 8122*

This means **you** decide on the level of your contribution to the Register.

You can add to, withdraw or change your level of consent by submitting a revised **Consent Form**. There is no charge or limit to these changes.

Withdrawing consent from the Register will not disadvantage you in any way or affect services you are currently receiving.

You control and “own” your information.

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Associated Conditions

Epilepsy

Western Australian recorded that the percentage of epilepsy among people with cerebral palsy had reduced from 45.5 percent in 1960-64 to 30.3 percent in 1990-94. In 2003, South Australia recorded 25 percent of people with cerebral palsy had epilepsy.

During a seizure the normal, orderly pattern of electrical activity in the brain is disrupted by uncontrolled bursts of electricity. When seizures occur without a direct trigger, such as fever, the condition is called epilepsy.

Vision Impairment

Blindness has dropped from 13.9 percent in 1960-64 to 8.8 percent in 1990-94 according to Western Australia data. In 2003 South Australia data recorded that 38 percent of people with cerebral palsy have visual problems – not just blindness.

A large number of children with cerebral palsy have strabismus, a condition in which the eyes are not aligned because of differences in the eye muscles. Some children can have hemianopia, which is defective vision or blindness that impairs the normal field of vision. When hemianopia affects only the right field of the right eye, a child looking straight ahead might have perfect vision except on the far right.

Hearing Impairment

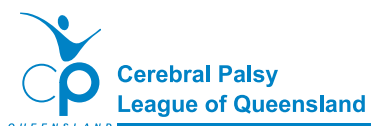
Deafness has also been reduced from 6.9 percent in 1960-64 to 3.7 percent in 1990-94. In 2003 South Australian data recorded that 15 percent of people with cerebral palsy have hearing problems - not just deafness.

Hearing problems are usually grouped into two types: conductive and sensorineural. Conductive hearing loss means that there is a problem with the middle or outer ear, which prevents the sound from physically reaching the healthy auditory nerve. Sensorineural hearing loss is damage to the auditory nerve or inner ear, preventing the brain from receiving the correct signals.

Intellectual Impairment

Intellectual impairment has also dropped from 59.4 percent in 1960-64 to 38.8 percent in 1990-94 according to Western Australian data which defines intellectual impairment as an IQ of less than 70. In 2003 South Australian data recorded that 42.6 percent of people with cerebral palsy have "mild to profound" intellectual impairment.

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Population Trends

Spastic Cerebral Palsy

According to Western Australian data there was no overall change in the incidence of spastic cerebral palsy from 1960-64 to 1990-94. The table below shows the rate of spastic cerebral palsy per 1000 live births from 1960-64 and 1990-94.

Birthweight	1960-64	1990-94	Change
Less than 1500g	15.7	47.7	+32
1500g-2499g	8.71	6.16	-2.55
Greater than 2500g	1.2	1.06	-0.14

The main change was in the group whose birthweight was less than 1500g. This was a very small section of the population so changes in this group had very little effect on the overall incidence of cerebral palsy. Diplegia rose from 9.66 to 21.76 per 1000 live births. Hemiplegia rose from 6.04 to 25.10 per 1000 live births. Quadriplegia consistently had low numbers rising from zero to 0.83 per 1000 live births.

Non-Spastic Cerebral Palsy

Western Australian data suggests there was an increase in the number of people per 1000 live births with non-spastic cerebral palsy between 1960-64 and 1990-94.

Type of non-spastic CP	1960-64	1990-94	Change
Ataxia	0.24	0.20	-0.04
Dyskinesia	0.25	0.37	+0.12

Dyskinesia increased in the group whose birthweight was equal to or greater than 2500g from 0.13 per 1000 live births in 1960-64 to 0.28 per 1000 live births in 1990-94.

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