

Australian Cerebral Palsy Register 2020 Bulletin

Rates and trends for prenatally and perinatally acquired cerebral palsy, birth years 1995-2014










What is the Australian Cerebral Palsy Register?

The Australian Cerebral Palsy Register (ACPR) is an electronic database of data uploaded from the CP Registers in each state and territory of Australia, from which individual identifiers have been removed and replaced by a unique code in order to ensure privacy of data.

The Australian Cerebral Palsy Register (ACPR) Group sincerely thanks all the families and health professionals involved in this Australia wide effort. In these endeavours, we aim to collect the most accurate and complete data possible to monitor cerebral palsy (CP) in Australia, identify causal pathways, evaluate preventive strategies and evaluate management options for those with CP and their families.

The ACPR is hosted by the Cerebral Palsy Alliance Research Institute in Sydney, with ethical oversight by The University of Sydney Human Research Ethics Committee and the Aboriginal Health and Medical Research Council of New South Wales. The ACPR is funded by the Cerebral Palsy Alliance Research Foundation. Additionally the ACPR Senior Research Fellow receives salary support from the Australasian Cerebral Palsy Clinical Trials Network.

The ACPR exists as a result of collaborative partnerships between all the Australian state and territory CP registers, and the organisations which support each register:

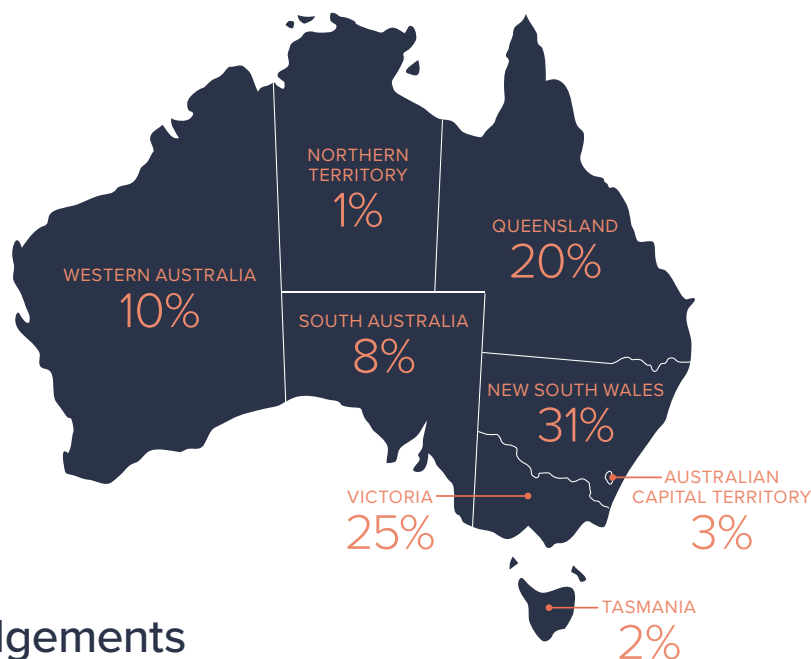
<p>Shona Goldsmith*, Sarah McIntyre*, Hayley Smithers-Sheedy*, Nadia Badawi, Isabelle Balde, Petra Karlsson, Iona Novak, Katarina Ostojic and Emma Waight</p> <p>cpregister@cerebralpalsy.org.au</p>	<p>ACPR/ Australian Capital Territory/ New South Wales (ACT/NSW) Cerebral Palsy Registers</p> <p>Est 2005</p>	<p>Cerebral Palsy Alliance Research Institute, The University of Sydney</p>	
<p>Fiona Kay* and Cassie Goldsworthy</p> <p>CPRegister.THS@nt.gov.au</p>	<p>Northern Territory (NT) Cerebral Palsy Register</p> <p>Est 2008</p>	<p>Women, Children & Youth, Royal Darwin Hospital</p>	
<p>Megan Auld* and Jacinta Quartermaine</p> <p>cpregister@cplqld.org.au</p>	<p>Queensland (QLD) Cerebral Palsy Register</p> <p>Est 2006</p>	<p>Choice, Passion, Life</p>	
<p>Catherine Gibson*, Heather Scott* and Jennifer Hernandez</p> <p>cywhs.cpregister@health.sa.gov.au</p>	<p>South Australian (SA) Cerebral Palsy Register</p> <p>Est 1998</p>	<p>Women's and Children's Health Network</p>	
<p>Eliza Maloney*, Nadine Davies, Marie Rauter and Lynne Jones</p> <p>society@stgiles.org.au</p>	<p>Tasmanian (TAS) Cerebral Palsy Register</p> <p>Est 2008</p>	<p>St Giles</p>	
<p>Sue Reid*, Gina O'Grady, Angela Guzys and Dinah Reddihough</p> <p>vic.cpregister@rch.org.au</p>	<p>Victorian (VIC) Cerebral Palsy Register</p> <p>Est 1986</p>	<p>Murdoch Children's Research Institute at the Royal Children's Hospital</p>	
<p>Linda Watson*, Eve Blair, Noula Gibson, Dylan Gratton, Katherine Langdon and Sarah Love</p> <p>Linda.Watson@health.wa.gov.au</p>	<p>Western Australian (WA) Register of Developmental Anomalies - Cerebral Palsy</p> <p>Est 1977</p>	<p>Department of Health Western Australia</p>	

* ACPR Policy Group Members

Reporting

In order to provide timely reporting of CP data, this short bulletin provides a snap-shot of rates for prenatally and perinatally acquired CP, birth years 1995-2014. Combined rates in this report are reported from the three long-standing registers in South Australia, Victoria and Western Australia.

A map showing the states and territories and the percentage of total population has been provided below. Australia has a total population of over 25 million people, with approximately 315,000 births per year.



Acknowledgements

Thank you to all members of the ACPR Policy Group for their expertise, time and commitment in collecting, verifying and providing data, attending meetings, participating in working groups and writing this report. Thank you also to the members of the Community, Aboriginal and Torres Strait Islander Reference Group who provide guidance and support to the ACPR.



Members of the Australian Cerebral Palsy Register Group with colleagues from the Bangladesh Cerebral Palsy Register, the New Zealand Cerebral Palsy Register, the Sri Lankan Cerebral Palsy Register and the Surveillance of Cerebral Palsy in Europe.

Prenatally and perinatally acquired cerebral palsy

Table 1. Ascertained numbers and rates of children with CP per 1000 live births (LB) for each Australian state/territory of birth by birth period (1995-2014)

	1995-96	1997-98	1999-00	2001-02	2003-04	2005-06	2007-08	2009-10	2011-12	2013-14	Total
ACT/NSW											
CP Cases	211	290	275	319	301	313	326	292	281	234	2842
CP cases/1000 LB	1.2	1.6	1.5	1.8	1.7	1.6	1.6	1.4	1.4	1.1	
NT											
CP Cases	11	12	17	8	16	9	11	13	14	10	121
CP cases/1000 LB	1.6	1.7	2.2	1.1	2.3	1.2	1.5	1.7	1.8	1.3	
QLD											
CP Cases	156	141	149	125	183	173	210	194	166	108	1605
CP cases/1000 LB	1.6	1.5	1.5	1.3	1.8	1.6	1.7	1.6	1.3	0.9	
SA											
CP Cases	83	95	76	52	58	77	77	80	59	50	707
CP cases/1000 LB	2.2	2.6	2.1	1.5	1.7	2.1	2.0	2.0	1.4	1.2	
TAS											
CP Cases	8	10	12	18	19	17	22	30	10	11	157
CP cases/1000 LB	0.6	0.8	1.0	1.6	1.7	1.4	1.7	2.4	0.8	0.9	
VIC											
CP Cases	226	237	232	259	231	247	226	228	196	211	2293
CP cases/1000 LB	1.8	1.9	1.9	2.1	1.8	1.8	1.6	1.6	1.3	1.4	
WA											
CP Cases	117	144	147	122	121	157	133	125	116	106	1288
CP cases/1000 LB	2.3	2.8	2.9	2.5	2.4	2.8	2.2	2.0	1.8	1.5	
ALL STATES AND TERRITORIES COMBINED											
CP Cases	812	929	907	903	929	993	1005	962	842	730	9013
CP cases/1000 LB	1.6	1.8	1.8	1.8	1.8	1.8	1.7	1.6	1.4	1.2	
SA, VIC and WA COMBINED											
CP Cases	426	476	455	433	410	481	436	433	371	367	4288
Live births	214820	211297	211150	208960	211055	227237	243393	248004	257360	265933	
CP cases/1000 LB	2.0	2.3	2.2	2.1	1.9	2.1	1.8	1.7	1.4	1.4	
(95% CI)	(1.8, 2.2)	(2.1, 2.5)	(2.0, 2.4)	(1.9, 2.3)	(1.8, 2.1)	(1.8, 2.1)	(1.9, 2.3)	(1.6, 1.9)	(1.3, 1.6)	(1.2, 1.5)	

Figure 1. Rates of children with CP per 1000 live births (LB) by birth period and state/territory of birth (1995-2014)

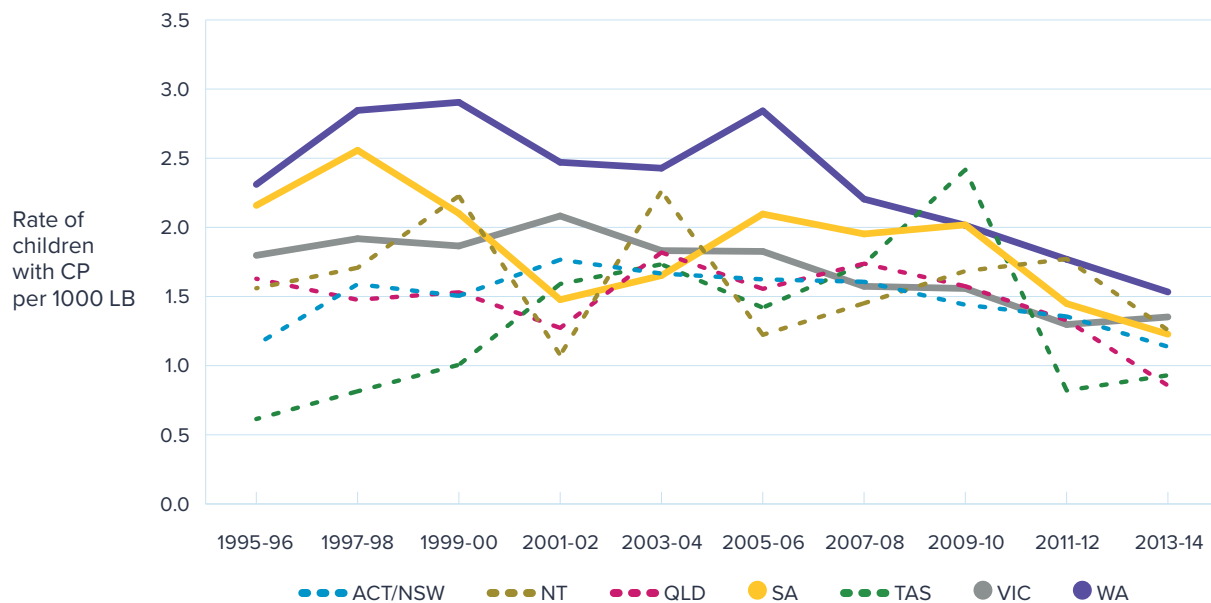
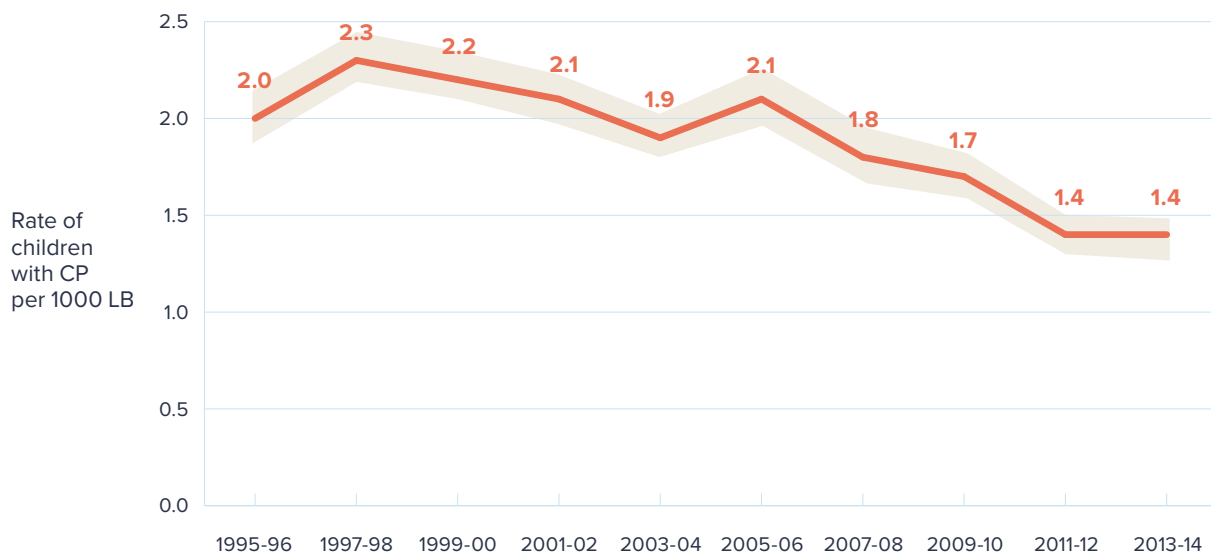


Figure 2. Rates of children with CP per 1000 live births (LB) with 95% CI, by birth period for South Australia, Victoria and Western Australia combined (1995-2014)



Since the last ACPR report in 2018, two additional birth years 2013-2014 have been included.

Figure 2 reporting combined data from South Australia, Victoria and Western Australia shows that the recent decline in the rate of CP has been sustained.

The rate of prenatally and perinatally acquired CP in Australia is 1.4 per 1000 live births.

Table 1 shows the same pattern of declining rates of CP in all states and territories.

Table 2. Rate of children with CP per 1000 live births (LB)/neonatal survivors (NNS) with 95% CI, by grouped gestational age at birth (weeks) and birth period, South Australia, Victoria and Western Australia combined (1995-2014)

	1995-96	1997-98	1999-00	2001-02	2003-04	2005-06	2007-08	2009-10	2011-12	2013-14
22-27 weeks n=505										
Rate/LB	64.6	78.1	58.4	48.1	47.6	42.2	42.8	50.6	29.7	33.7
(95% CI)	(50.4, 82.5)	(62.3, 97.6)	(45.2, 75.3)	(36.4, 63.4)	(36.1, 62.6)	(32.0, 55.5)	(32.5, 56.1)	(39.4, 64.9)	(21.1, 41.6)	(24.7, 45.7)
Rate/NNS	111.7	122.6	93.7	81.6	78.3	70.5	67.4	79.5	46.5	53.4
(95% CI)	(87.6, 141.5)	(98.2, 152.0)	(72.7, 120.0)	(61.9, 106.8)	(59.6, 102.3)	(53.6, 92.2)	(51.4, 88.0)	(62.0, 101.3)	(33.1, 64.9)	(39.3, 72.2)
28-31 weeks n=604										
Rate/LB	38.0	39.8	40.8	34.4	40.1	32.0	44.1	35.9	25.1	28.8
(95% CI)	(29.4, 49.0)	(31.2, 50.6)	(32.1, 51.7)	(26.5, 44.6)	(31.3, 51.3)	(24.7, 41.4)	(35.6, 54.6)	(28.4, 45.2)	(18.8, 33.3)	(22.3, 37.1)
Rate/NNS	39.5	41.4	42.2	35.5	41.1	32.7	45.3	36.6	25.6	29.4
(95% CI)	(30.4, 50.9)	(32.5, 52.6)	(33.2, 53.4)	(27.3, 46.0)	(32.1, 52.5)	(25.2, 42.4)	(36.5, 56.0)	(29.0, 46.2)	(19.3, 34.0)	(22.8, 37.9)
32-36 weeks n=670										
Rate/LB	4.6	5.2	4.9	4.0	4.1	5.5	4.8	4.7	3.8	4.0
(95% CI)	(3.5, 5.9)	(4.1, 6.6)	(3.8, 6.3)	(3.1, 5.3)	(3.1, 5.3)	(4.4, 6.8)	(3.9, 6.0)	(3.8, 5.9)	(3.0, 4.9)	(3.2, 5.1)
Rate/NNS	4.6	5.2	4.9	4.0	4.1	5.5	4.8	4.7	3.8	4.1
(95% CI)	(3.6, 6.0)	(4.1, 6.6)	(3.9, 6.3)	(3.1, 5.3)	(3.1, 5.3)	(4.4, 6.9)	(3.9, 6.0)	(3.8, 5.9)	(3.0, 4.9)	(3.2, 5.1)
37+ weeks n=2520										
Rate/LB	1.3	1.3	1.4	1.3	1.2	1.4	1.1	1.1	1.1	0.9
(95% CI)	(1.1, 1.4)	(1.2, 1.5)	(1.2, 1.6)	(1.1, 1.4)	(1.1, 1.4)	(1.2, 1.5)	(1.0, 1.3)	(0.9, 1.2)	(0.9, 1.2)	(0.8, 1.1)
Rate/NNS	1.3	1.3	1.4	1.3	1.2	1.4	1.1	1.1	1.1	0.9
(95% CI)	(1.1, 1.4)	(1.2, 1.5)	(1.2, 1.6)	(1.1, 1.4)	(1.1, 1.4)	(1.2, 1.5)	(1.0, 1.3)	(0.9, 1.2)	(0.9, 1.2)	(0.8, 1.1)

Explanatory note regarding rates per 1000 neonatal survivors:

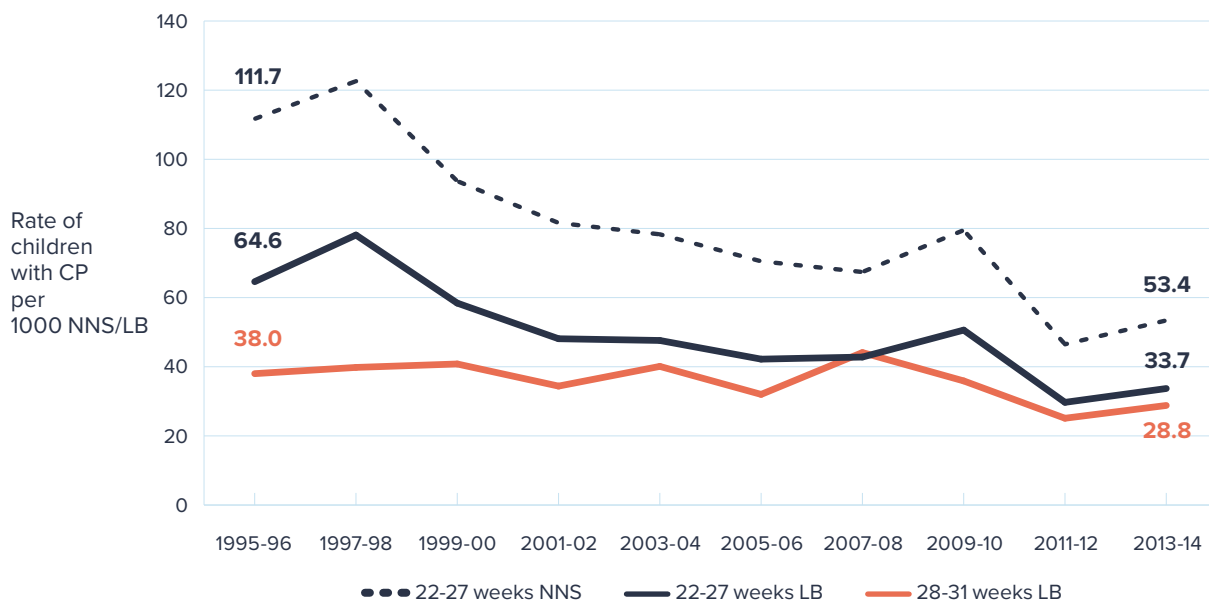
In Table 2 and Figure 3a you will note that the rate of CP per 1000 neonatal survivors* for those born extremely preterm* is higher than the rate of CP per 1000 live births*. This reflects the higher number of neonatal deaths* in extremely preterm babies compared with the other gestational age groups, where rates per live births and neonatal survivors are either very similar or the same.

*See glossary

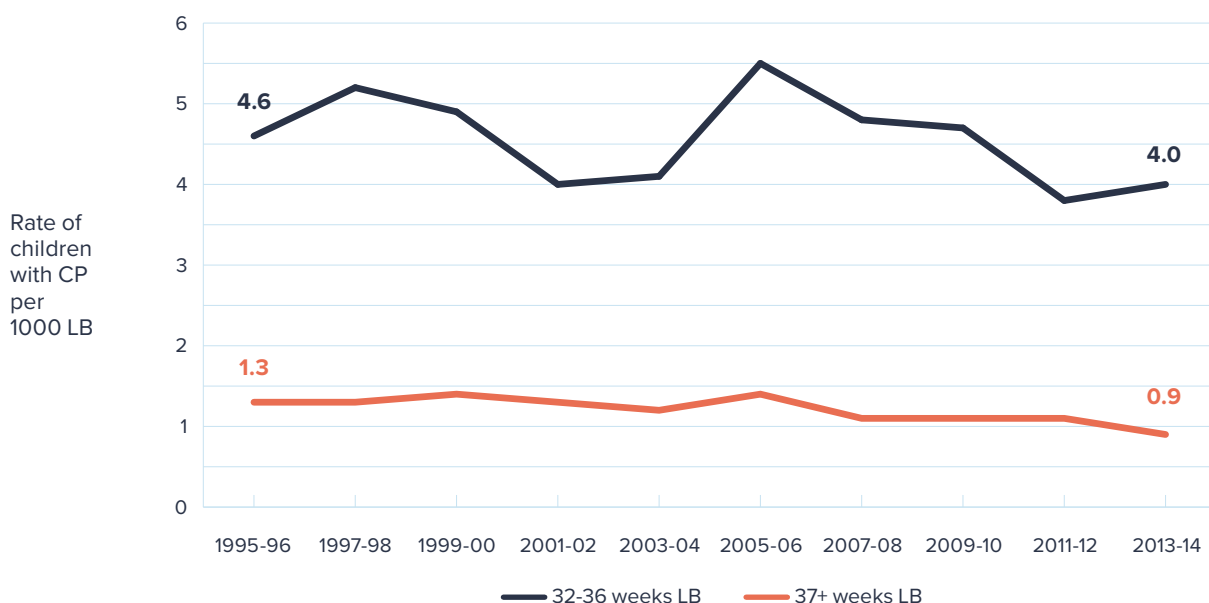


Figures 3a/b. Rate of children with CP per 1000 live births (LB)/neonatal survivors (NNS), by grouped gestational age at birth and birth period, South Australia, Victoria and Western Australia combined (1995-2014)

3a. Extremely and very preterm births



3b. Moderately preterm and term births



Among children born extremely and very preterm there was a slight increase in rates of CP for the 2013-2014 birth years. However, these rates were still lower than all rates for these groups prior to 2011-2012.

Term births are the largest gestational age group accounting for 59% of all children with CP. The rate of CP in this group continued to decline in the 2013-2014 birth years.

Affiliated cerebral palsy registers

Bangladesh Cerebral Palsy Register, established 2015

Aims: To establish a platform for a national CP register in Bangladesh and to:

- Determine the prevalence of CP in Bangladesh
- Determine the aetiology to identify preventable causes
- Systematically assess severity and associated impairments
- Complete a needs assessment and develop a framework for service delivery

Investigators: Gulam Khandaker, Mohammad Muhit, Tasneem Karim, Hayley Smithers-Sheedy, Israt Jahan, Manik Chandra Das, Mahmudul Hassan Al Imam, Iona Novak and Nadia Badawi



Contact: Tasneem Karim

Email: Tasneem.karim@health.nsw.gov.au

Web: bangladesh.cpregister.com



New Zealand Cerebral Palsy Register, established 2016

Aims: To use the NZCPR assist with:

- Describing the NZ CP population to assist with health and education service planning and delivery
- Identify inequities within our Indigenous and minority populations
- Promote and facilitate research in the field of CP, with a focus on inequity
- Improving utility and expansion of collecting data that informs clinical practice and monitors outcomes for children with CP

Investigators: Susan Stott, Anna Mackey, Alexandra Sorhage



Contact: Alexandra Sorhage

Email: nzcpregister@adhb.govt.nz

Web: nz.cpregister.com



Sri Lankan Cerebral Palsy Register, established 2017

Aims:

- To establish a secure web-based Sri Lankan CP Register (SLCPR) for hospital and community-based surveillance of CP in Sri Lanka.
- To utilise SLCPR data to describe
 - demographic features
 - CP prevalence
 - timing of brain injury
 - clinical profile
 - use and access to rehabilitation services
 - aetiology of CP



Investigators: Samanmali Sumanasena, Gopi Kitnasamy, Thilini Madushika, Hayley Smithers-Sheedy, Romaniya Fernando, Nimisha Muttiah, Jayatri Jagoda, Saraji Wijesekara, Pyara Ratnayaka, Jithangi Wanigasinghe, Nilathi De Silva, Shyamini Hettiarachchi, Gulam Khandaker, Ranmali Waduge, James Rice, Sarah McIntyre, Shona Goldsmith and Mohammed Muhit

Contact: Thilini Madushika and Romaniya Fernando
Email: srilankacpregister@gmail.com
Web: srilanka.cpregister.com



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Cerebral Palsy Lanka Foundation





Glossary

Live birth

A live birth occurs when a fetus, whatever its gestational age, exits the maternal body and subsequently shows any sign of life, such as voluntary movement, heartbeat or pulsation of the umbilical cord, for however brief a time and regardless of whether the umbilical cord or placenta are intact. The live birth denominator data used in this report captures all live births of at least 20 weeks gestation or, if gestation is unknown, at least 400 grams birth weight.

Neonatal death

Death of a live born baby within 28 days of birth.

Neonatal survivor

A baby who is alive beyond 28 days of birth is a neonatal survivor. In this report neonatal survivor denominator data is equal to the number of live births minus the number of neonatal deaths.

Prenatally or perinatally acquired cerebral palsy

Cerebral palsy resulting from brain maldevelopment or injury during the prenatal or perinatal period (throughout pregnancy and during the first 28 completed days after birth).

Preterm birth

A baby born alive before 37 weeks of pregnancy is completed.

The sub-categories of preterm birth, based on gestational age are:

- extremely preterm (less than 28 weeks)
- very preterm (28-31 weeks)
- moderately preterm (32–36 weeks)



Australian Cerebral Palsy Register
T: 02 9475 8000
E: cpregister@cerebralpalsy.org.au
W: cpregister.com

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