

AUSTRALIAN CEREBRAL PALSY REGISTER

Report 2013



Cerebral Palsy
ALLIANCE
RESEARCH INSTITUTE



Register

Piecing together the facts on cerebral palsy

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ACKNOWLEDGEMENTS

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 in Australia, identify causal pathways, evaluate preventive strategies and evaluate management options for those with cerebral palsy and their families.

The ACPR Group acknowledges and thanks Hayley Smithers-Sheedy, Research Officer for the ACPR for developing, coordinating and writing this report, and Renée Price for its design. The ACPR is hosted at the Cerebral Palsy Alliance Research Institute in Sydney and funded by the Cerebral Palsy Alliance Research Foundation.

The staff at the Cerebral Palsy Alliance Research Institute would like to thank all members of the ACPR Policy Group for their expertise, time and commitment shown over the last twelve months while uploading data, attending meetings, participating in working groups and writing this report. The ACPR exists as a result of collaborative partnerships between all the Australian state and territory cerebral palsy registers, and the organisations which support each register. The contributing registers and their organisations are as follows:

- Australian Capital Territory and New South Wales Cerebral Palsy Registers - Cerebral Palsy Alliance Research Institute
- Northern Territory Cerebral Palsy Register - Centre for Disease Control
- Queensland Cerebral Palsy Register - Cerebral Palsy League and Queensland Health
- The South Australian Cerebral Palsy Register - Women's and Children's Health Network
- Tasmanian Cerebral Palsy Register - Cerebral Palsy Alliance Research Institute and St Giles
- Victorian Cerebral Palsy Register - Murdoch Childrens Research Institute, Royal Children's Hospital, Melbourne
- Western Australian Register of Developmental Anomalies - Cerebral Palsy - Department of Health WA





FOREWORD



The first cerebral palsy register and the first birth defects register in Australia were established in Western Australia in 1979 and 1980, respectively. Both were set up by Fiona Stanley, both have proven valuable for research and health service evaluation and planning, and both have been used as templates for other similar registers across the country. These WA registers had voluntary notification from multiple sources, resulting in high levels of case ascertainment. Notification did not require parental consent and whilst this may have been acceptable in the early 1980s, as time went on it was no longer so.

Through a series of consumer and community consultations, which included representatives of several support groups for families of children with cerebral palsy or birth defects and the Health Consumers' Council of WA, a unanimous decision in favour of statutory notification was reached. Participants valued highly the opportunity to contribute to the process and the Executive Director of the Health Consumers' Council of WA noted that this was the first time that the community had been invited to give input into the reporting process of a register in WA. Statutory notification ensures the security of the data collection and formally acknowledges its value. It has been well documented that consent-based registers under-ascertain, so another advantage of a statutory register is that it allows notification without the need to seek consent (often at a time when parents are distressed).

Consumers continued their involvement through reviewing drafts of the Regulations, coming up with a new name for the combined register (WA Register of Developmental Anomalies, to better reflect the two groups of conditions – birth defects and cerebral palsy), devising a means of removing identifying information from the Register if requested by parents or affected individuals and assisting in development and updating of the Register's website. The Regulations were gazetted in January 2011. The new Register has an active Consumer Reference Group (CRG). One of its valuable functions relates to research using register data - CRG members review research applications, provide advice to researchers and request a lay summary of each research project. Another way consumers contribute is to suggest topics for research and this has been beautifully exemplified in cerebral palsy, where consumers were equal members of a panel to identify priorities for cerebral palsy research^[1]. People with cerebral palsy and their families know more about cerebral palsy than almost anyone else. I commend the ACPR to include them as equal partners in this invaluable collaboration.

I congratulate the ACPR on a great achievement - collaboration across the country to support the establishment of registers in states where one did not previously exist and to combine data on cerebral palsy for research to assist in reducing the incidence of cerebral palsy and enhancing the quality of life of those living with cerebral palsy.

A blue ink signature of Dr. Carol Bower, written in a cursive style.

Dr Carol Bower

Head

Western Australian Register of Developmental Anomalies



EXECUTIVE SUMMARY

The Australian Cerebral Palsy Register (ACPR) is a research database developed to facilitate the study of the distribution, frequency and severity of cerebral palsy; the causes and determinants of cerebral palsy; the effectiveness of prevention strategies and to help plan and evaluate services. The data stored in the database are de-identified and securely uploaded from each state and territory cerebral palsy register in Australia.

This is the second report of combined state data sets and for the first time, we are able to cautiously start reporting trends. The data pertain to birth years 1993-2006. For this report, data was uploaded to the ACPR database in June 2012. Any cases notified to state/territory registers after this date were not included in this report.

Data ascertainment varies between states, reflecting differences in both the time of establishment and the governance of each register. Three states of Australia - Western Australia, Victoria and South Australia have long established cerebral palsy registers. They are considered "population registers" as they are believed to have registered all (or very nearly all) eligible persons. The population registers' data have been combined in this report. Cerebral palsy registers have been established more recently in the Australian Capital Territory, New South Wales, Northern Territory, Queensland and Tasmania. Pleasingly, their ascertainment rates are increasing rapidly. However, their data are not yet able to be combined with the population registers and are presented throughout the report in tables only.

There were 3135 individuals with cerebral palsy born 1993-2006 on the population registers, a prevalence of 2.1/1000 live births (95%CI 2.0-2.2). For 5.6% of individuals, their brain injury was acquired during a recognised event occurring more than 28 days after birth. The predominant cause for this group was a cerebro-vascular accident (34.2%) being spontaneous, associated with surgery or with complications of cardiac defects.

For the remaining 94.4% of individuals, the brain injury responsible for cerebral palsy is believed to have occurred during the prenatal and perinatal period of infant development and the prevalence of this group was 2.0/1000 live births (95%CI 1.9-2.1). The following key findings pertain to this cohort.

- Compared with the Australian population in which 8.2% were born before 37 weeks' gestation (premature), 41.3% of this cerebral palsy cohort were born premature.
- Importantly, all three states showed a reduction in rates over time in the 20-27 week gestational age group but for all other gestational age groups the evidence is not yet strong enough to suggest systematic time trends in prevalence.
- Similarly, compared with the Australian population in which 6.4% are born with weights below 2500g (low birth weight), 41.7% of infants with cerebral palsy were born with a low birth weight. Prematurity and low birth weight are associated with multiple births: 11.9% of this cerebral palsy cohort were part of a multiple birth compared with 3.3% of births in the Australian population.
- There was an excess of males; 57.3% of the cohort were male compared to 51% of births in Australia. In addition, the ethnicity of 3.5% of mothers was Aboriginal and/or Torres Strait Islander compared to approximately 2.5% in the three combined states.
- Spasticity was the predominant motor type of cerebral palsy (86.6%). Of individuals with a spastic motor type, 38.8% had unilateral spasticity (hemiplegia/monoplegia) and 61.2% had bilateral spasticity (diplegia, triplegia and quadriplegia).
- Associated impairments occurred frequently in children with cerebral palsy. At the age of five: 30% had epilepsy; >50% had intellectual impairment; 60% had speech impairment; 40% had visual impairment and 10% had hearing impairment.

The ACPR group has identified and will investigate a number of important differences between the three states with population registers:

- Western Australia had a prevalence of 2.5 per 1000 live births (95%CI 2.4-2.7) which was notably higher than the South Australian or Victorian rates of 1.8/1000 live births.
- In term births (37 weeks or more) Western Australia reported a higher rate of CP (1.5-1.9 per 1000 live births) than South Australia (0.8-1.1 per 1000 live births) and Victoria (1.0-1.2 per 1000 live births).
- There appeared to be a declining rate of CP in singletons in South Australia and Victoria but not in Western Australia.
- South Australia reported a higher proportion of cases with spasticity (94.3%) while Victoria and Western Australia have increased proportions of dyskinesia.



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ABOUT CEREBRAL PALSY

There has been ongoing debate in recent times as to how best to define cerebral palsy (CP)^[2]. Both internationally and in Australia, CP registers have drawn on a range of references and perspectives when considering the definition which best suits their purposes^[3]. The ACPR has adopted the approach used by the Surveillance of Cerebral Palsy in Europe (SCPE)^[4], allowing the use of any definition that includes the following five key elements common to the definitions published by Bax^[5], Rosenbaum^[2] and Mutch^[6].

Cerebral palsy:

- (1) is an umbrella term for a group of disorders
- (2) is a condition that is permanent but not unchanging
- (3) involves a disorder of movement and/or posture and of motor function
- (4) is due to a non-progressive interference, lesion, or abnormality, and
- (5) the interference, lesion, or abnormality originates in the immature brain^[4].

For the majority of individuals with CP their complete causal pathway to brain injury is not well understood. CP is associated with numerous perinatal factors e.g., rubella or cytomegalovirus infections, birth defects, preterm birth, intrauterine growth restriction, sentinel events and multiple pregnancy, and with post-neonatal factors such as head trauma or cerebral infections^[7].

Motor disability ranges from minimal to profound, and disability can be exacerbated by a wide range of associated impairments^[8,9]. The likelihood and severity of associated impairments increase with the severity of motor impairment^[10-12]. Some researchers have suggested that associated impairments can be more detrimental to quality of life than the motor impairment^[13]. Meta-analyses which calculated the overall rates of associated impairments and functional limitations in the CP population show the following: 3 in 4 are in pain; 1 in 2 has an intellectual disability; 1 in 3 cannot walk; 1 in 3 has a hip displacement; 1 in 4 cannot talk; 1 in 4 has epilepsy; 1 in 4 has a behaviour disorder; 1 in 4 has a bladder control problems; 1 in 5 has a sleep disorder; 2 in 5 dribble; 1 in 10 is blind; 1 in 15 is tube fed; and 1 in 25 is deaf^[14].

Many will have more than one associated impairment, and their presence complicates therapy, decreases health status and quality of life for the individual and their family, and increases costs for the family and to society^[8,15].

Estimates of prevalence of CP throughout the world vary depending on the methodology of "count", percentage ascertained and variations in selection criteria. CP registers have identified rates ranging between 1.4-2.77/1000 live births; surveillance programs range between 2.1-3.6/1000 live births; and cross-sectional surveys range between 1.05 and 4.1/1000 live births^[8]. The two largest data sets, the ACPR and the SCPE both have an overall birth prevalence of around 2/1000 live births. Although CP is found across all socio-economic classes, there is a clear association between low birth weight and low socio-economic status. In the normal birth weight ranges, rates of CP are 2.42/1000 live births for those in the lowest socio-economic groups, compared to 1.29/1000 for the most affluent groups^[8].



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 client identifiers have been removed and replaced by a unique code in order to ensure privacy of data.

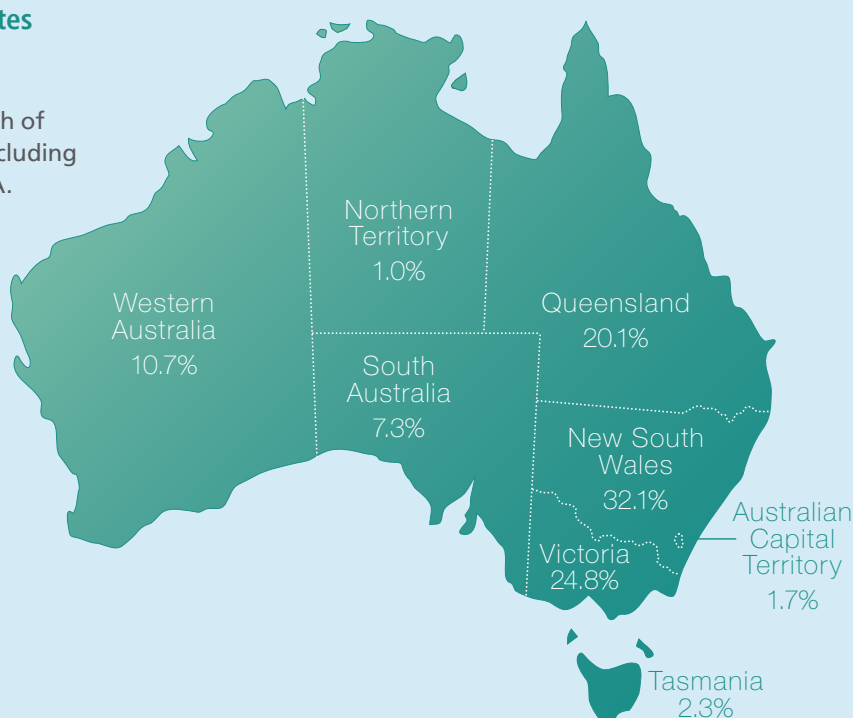
The ACPR exists as a result of collaborative partnerships between all Australian state and territory cerebral palsy registers, and the organisations which support each register. The contributing registers and their organisations are as follows:

- Australian Capital Territory (ACT) and New South Wales Cerebral Palsy Register (NSW)
- Cerebral Palsy Alliance Research Institute
- Northern Territory (NT) Cerebral Palsy Register
- Centre for Disease Control
- Queensland (QLD) Cerebral Palsy Register
- Cerebral Palsy League and Queensland Health
- The South Australian (SA) Cerebral Palsy Register
- Women's and Children's Health Network
- Tasmanian (TAS) Cerebral Palsy Register
- Cerebral Palsy Alliance Research Institute and St Giles
- Victorian (VIC) Cerebral Palsy Register
- Murdoch Childrens Research Institute, Royal Children's Hospital, Melbourne
- Western Australian (WA) Register of Developmental Anomalies – Cerebral Palsy
- Department of Health WA.

A map showing the states and territories and the percentage of total population has been provided below. Australia has a total population of approximately 22.5 million people¹⁶ with the bulk of the population living along the eastern seaboard.

Population proportions for the States and Territories of Australia¹⁶

For a more detailed description of each of the state and territory CP registers, including contact details, please see Appendix A.



AIMS OF THE ACPR

The overarching vision for the ACPR is that the register should be used to assist in efforts to both reduce the incidence of cerebral palsy and significantly enhance the quality of life of those living with cerebral palsy.

Specifically, the aim for the ACPR is to be a source of data that will support research relating to:

- a) monitoring of CP
- b) identifying interventions that effectively improve quality of life
- c) identifying causal pathways to enable prevention
- d) evaluating future preventive strategies.

The ACPR Research and Policy Group includes a representative from each state and territory CP register. This group is able to provide consultation to researchers who are seeking advice regarding cerebral palsy research and accessing identified and non-identified cerebral palsy register data within Australia. For further information please contact: cpregister@cerebralpalsy.org.au

Ethics

Contribution of data to the ACPR has been approved by the relevant Human Research Ethics Committee (HREC) overseeing each state and territory register. Additionally, both the management of ACPR data and the activities of, and work related to the ACPR is reviewed regularly by the Cerebral Palsy Alliance Research Committee (National Health and Medical Research Council (NH&MRC) approved HREC).

The Cerebral Palsy Alliance Research Institute is the custodian organisation for the ACPR. Both the Research Institute and the ACPR are funded by Cerebral Palsy Alliance Research Foundation which is a wholly owned company of Cerebral Palsy Alliance.

Current projects

In addition to their state and territory register responsibilities ACPR Policy Group members have worked, and continue to work with their international colleagues on a number of projects including:

- contribution of papers and participation in the World CP Registers, Surveys and Networks Day, part of the International Cerebral Palsy Conference in Pisa, 2012
- analysis of ACPR data of contributing causes to CP e.g. congenital cytomegalovirus ($\approx 1.4\%$ of pre/perinatal cases), syndromes ($\approx 0.5\text{--}1\%$ of pre/perinatal cases)
- development of the Intersect Forum site as a place where clinicians and researchers involved in registers and surveillance can pose questions and share both information and their expertise with others. Membership is free and available to any interested parties. For further information, please access the website impact.cerebralpalsy.org.au

The work of CP registers in Australia has added to our understanding of cerebral palsy and contributed significantly to research in this field. Please see Appendix C for a list of publications that have been generated by state CP registers in Australia since the publication of the 2009 ACPR report.



METHODS

Cohort

The cohort selected for this report was born 1993-2006. In order to ensure that duplicate cases were not included in the dataset, each state and territory group contributed only cases that were born in their state or territory within this time frame. A de-duplication algorithm designed to highlight potential duplicates was also run as a further measure to avoid reporting duplications.

Inclusion/exclusion criteria

In order to be included in the dataset, a case must fulfil the criteria contained in the five definitional elements⁴ as outlined previously.

Contributing registers consider cases to be confirmed when the individual reaches 5 years of age. In the event that new information becomes available a case entry may be updated, which may involve inclusion or exclusion.

Denominator data

Data on live births for the years 1993-2006 (the denominator) was obtained from a variety of sources including the Australian Institute of Health and Welfare – Consultative Council on Obstetric & Paediatric Mortality & Morbidity Annual Reports, the Australian Bureau of Statistics and Annual Reports of the Pregnancy Outcome Unit (SA).

Eligibility criteria for combining datasets

The level of ascertainment of cases achieved for each year 1993-2006 varied between each state and territory. This is due to a number of factors, including significant variation in the length of time registers have been in existence and differences in registrant consent requirements across the states and territories (see description of CP registers in Appendix A).

To avoid including significantly under-ascertained prevalence estimates, only data from those states or territories reporting a CP prevalence of at least 1.5/1000 live births across the cohort period were combined or compared excluding cases with a known post-neonatal cause (see Figure 1). State or territory cohort data that does not meet this criterion has been included in data tables only. Where more than 20% of data is missing or unknown, these data are reported in data tables only. While this figure of 1.5/1000 is somewhat arbitrary, it is based on the observation among the 3 longstanding CP registers that prevalence for the cohort is in excess of 1.5/1000 live births.

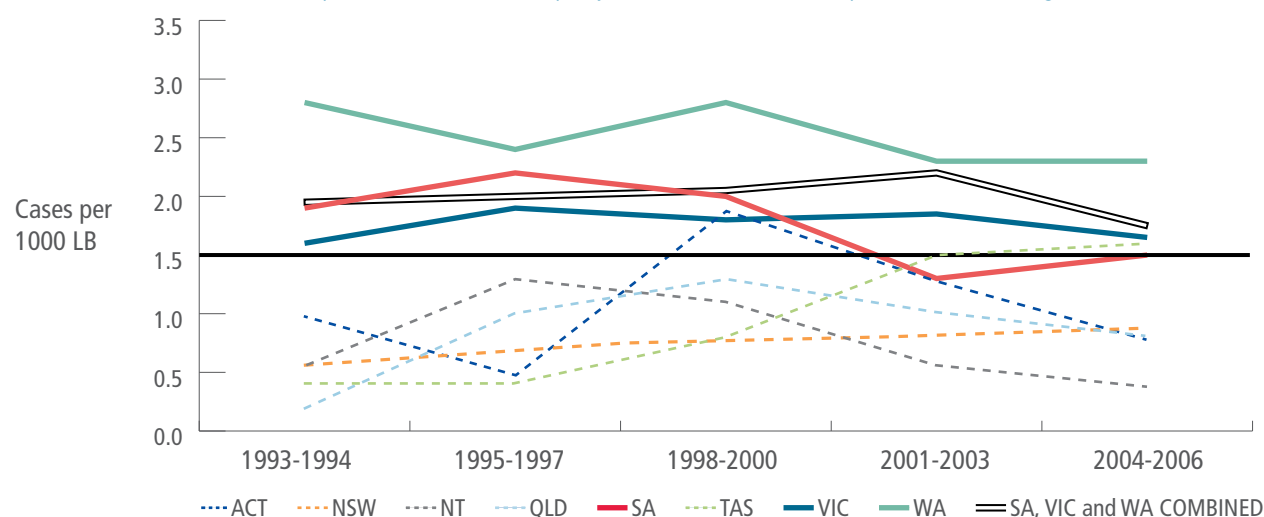
Please note, that percentages in tables may not equal 100% exactly due to rounding.

Results

The results of this report have been divided into three sections. Part 1 refers to all CP cases, Part 2 refers to CP arising from an injury to the developing brain during the pre/perinatal period (throughout pregnancy and the first 28 completed days after birth) and Part 3 refers to all CP cases where a known post-neonatal cause (occurring after 28 days of life and before 2 years of age) has been identified.¹⁷ The results have been presented in this format as the majority of pre/perinatal causes of CP are not well understood, whereas the likely proximal cause has been identified in post-neonatally acquired cases.

The ACPR began collecting Manual Ability Classification System (MACS) data too recently for this to be included in this report. It is expected that data pertaining to this classification system will be provided in future ACPR reports.

Figure 1. Birth prevalence of CP per 1000 live births by state and year of birth (1993-2006) excluding cases with a known post-neonatal cause, and the birth prevalence of cerebral palsy 1.5/1000 live births required for combining datasets





Prevalence

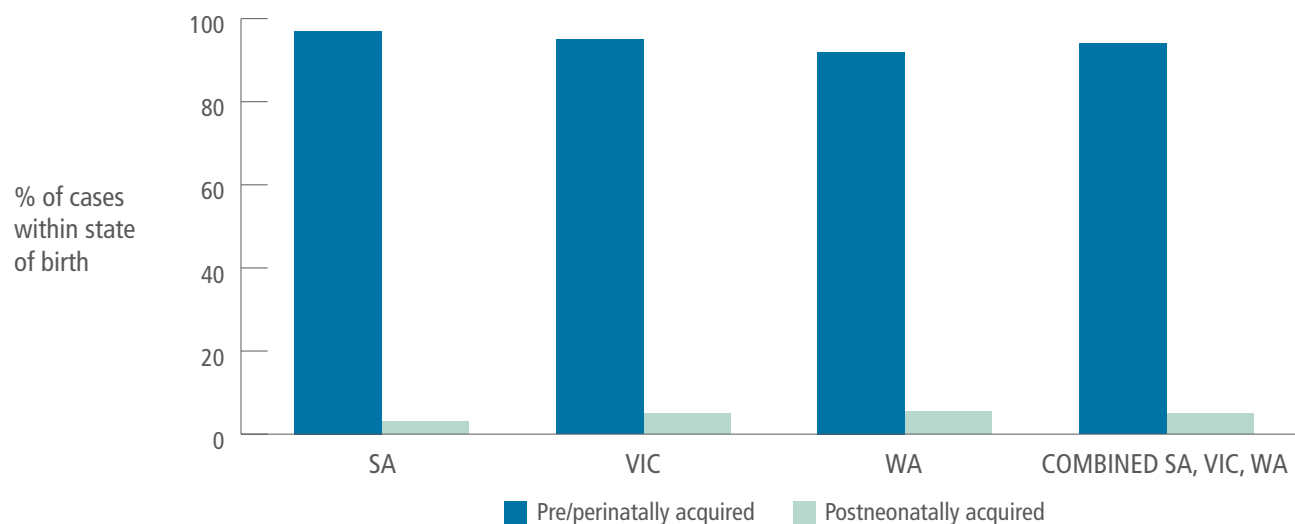
Table 1. Pre/perinatally and post-neonatally acquired cerebral palsy by state/territory of birth (1993-2006)

	Live births (1993-2006)	Pre/perinatally acquired CP	Post-neonatally acquired CP	TOTAL	Prevalence (per 1000 live births)
	n	n(%)	n(%)	CP n	All CP cases
ACT	61741	67(87.0)	10(13.0)	77	(1.2)
NSW	1222785	1013(89.7)	117(10.3)	1130	(0.9)
NT	51194	42(80.8)	10(19.2)	52	(1.0)
QLD	680348	655(95.8)	29(4.2)	684	(1.0)
SA	258340	461(96.8)	15(3.2)	476	1.8
TAS	85205	80(97.6)	*(2.4)	82	(1.0)
VIC	888155	1589(94.6)	90(5.4)	1679	1.9
WA	356693	910(92.9)	70(7.1)	980	2.7
TOTAL	2320138	4817	343	5160	-
COMBINED SA, VIC, WA	1503391	2960(94.4)	175(5.6)	3135	2.1

* < 5 cases

For this report of the Australian Cerebral Palsy Register, data pertaining to 5160 individuals with cerebral palsy are reported. The total prevalence for CP is 2.1 per 1000 live births (95% CI 2.0,2.2).

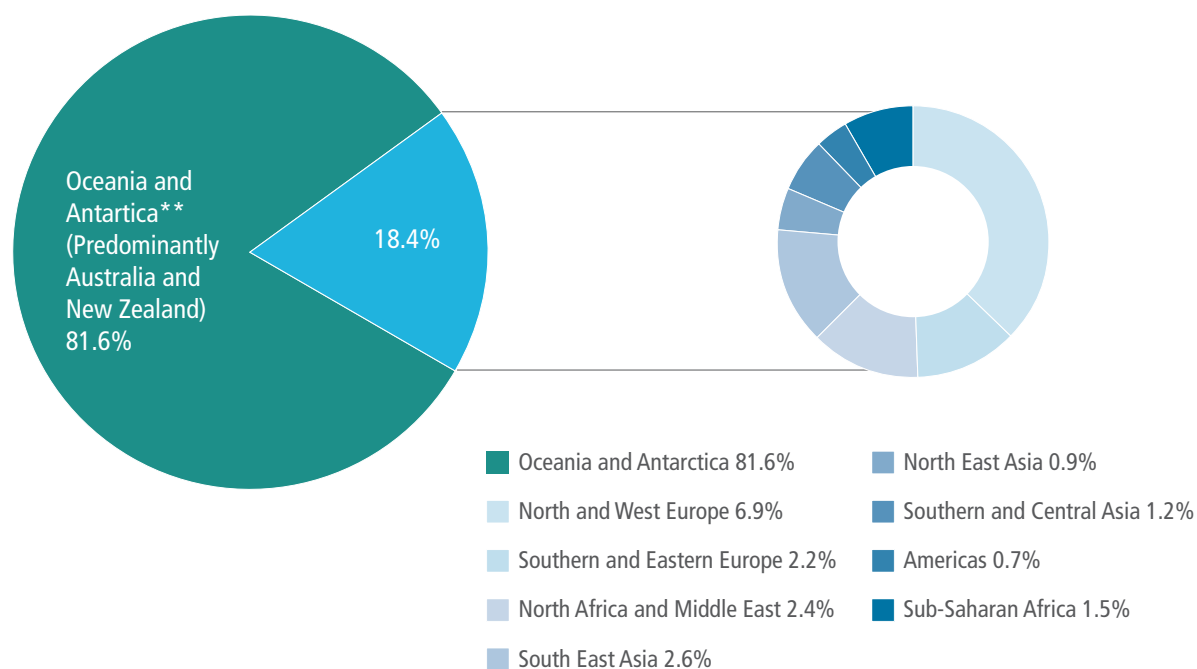
Figure 2. Percentages of pre/perinatally and post-neonatally acquired cerebral palsy by state/territory of birth (1993-2006)



Combined data indicate that the brain injury responsible for cerebral palsy primarily arises during the pre/perinatal period (94.4%). For a small group (5.6%) the brain injury occurred post-neonatally and before 2 years of age.

Maternal country of birth

Figure 3. Percentage of cerebral palsy cases born in South Australia, Victoria and Western Australia by mother's country of birth combined (1993-2006)



NB: ** Oceania and Antarctica Region includes: Australia, New Zealand, Melanesia, Micronesia, Polynesia and Antarctica



Indigenous status of mother

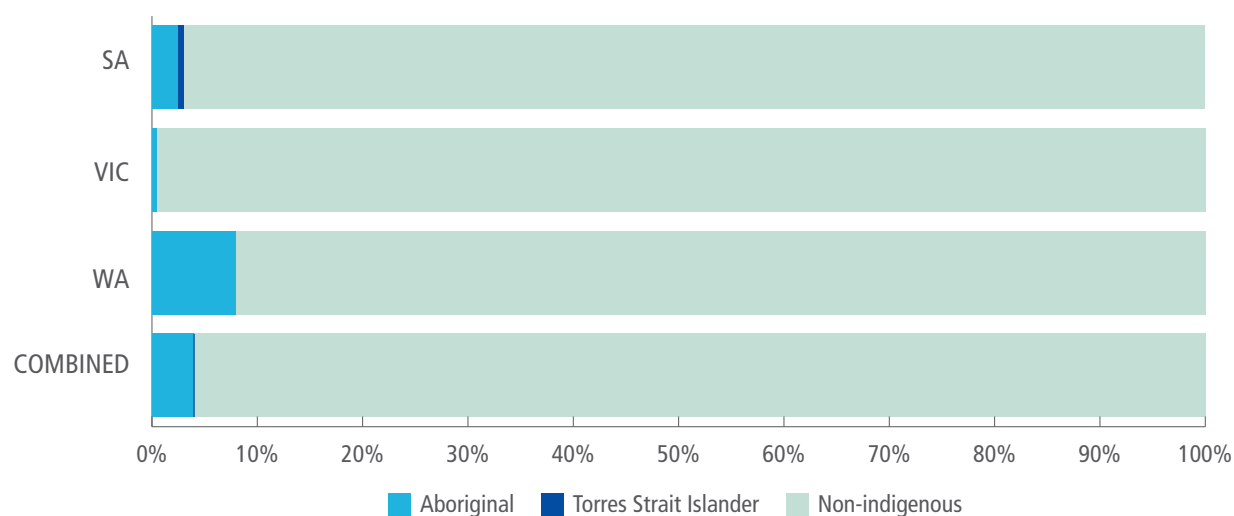
Table 2. Number and percentage of CP cases by indigenous status of mother and state/territory of birth (1993-2006)

	Aboriginal n(%)^	Aboriginal and Torres Strait Islander n(%)^	Torres Strait Islander n(%)^	Non-indigenous n(%)^	TOTAL n(%)	Unknown n(%)
ACT						
Pre/peri	*(3.8)	*	*	50(96.2)	67	15(22.4)
PNN cause	*(12.5)	*	*	7(87.5)	10	*(20.0)
NSW						
Pre/peri	41(4.1)	*(0.1)	*	748(94.7)	1013	223(22.0)
PNN cause	7(8.4)	*	*	76(91.6)	117	34(29.1)
NT						
Pre/peri	12(43.3)	*	*	24(66.7)	42	6(14.3)
PNN cause	8(88.9)	*	*	*(11.1)	10	*(10.0)
QLD						
Pre/peri	18(3.7)	*(0.8)	*(0.6)	456(94.8)	655	174(26.6)
PNN cause	*(16.0)	*	*	17(84.0)	27	*(7.4)
SA						
Pre/peri	12(2.6)	*	*(0.4)	443(96.9)	461	*(0.9)
PNN cause	*	*	*	15(100.0)	15	*
All cases	12(2.5)	*	*(0.4)	458(97.0)	476	*(0.8)
TAS						
Pre/peri	*(4.0)	*	*	72(96.0)	80	5(6.3)
PNN cause	*(100)	*	*	*	*	*
VIC						
Pre/peri	10(0.6)	*	*	1538(99.4)	1589	41(2.5)
PNN cause	*	*	*	90(100.0)	88	*
All cases	10(0.6)	*	*	1628(99.4)	1679	41(2.3)
WA						
Pre/peri	71(8.3)	*	*	787(91.7)	910	52(5.7)
PNN cause	14(23.0)	*	*	47(77.0)	70	9(12.9)
All cases	85(9.2)	*	*	834(90.8)	980	61(6.2)
COMBINED SA, VIC, WA						
Pre/peri	93(3.2)	*	*(0.1)	2768(96.7)	2960	97(3.3)
PNN cause	14(8.4)	*	*	152(91.6)	175	9(5.2)
All cases	107(3.5)	*	*(0.1)	2920(96.4)	3135	106(3.4)

* < 5 cases

(%)^ calculated by $n/(\text{total } n - \text{unknown } n)$; provided to allow state/territory comparisons

Figure 4. Percentage of CP cases by indigenous status of mother and state/territory of birth (1993-2006)



The combined data indicates that Aboriginal and/or Torres Strait Islander mothers are over-represented in this cohort of CP cases. They comprised 3.5% of the cohort compared to 2.5% of the total population in these states based on 2006 figures¹⁸. This group is particularly over-represented for post-neonatally acquired CP.



RESULTS:

2. Prenatally or perinatally acquired cerebral palsy cases

Part 2 of this report refers to cerebral palsy arising from an injury to the developing brain during the prenatal/perinatal period (throughout pregnancy and during the first 28 completed days after birth).

Table 3. Prevalence of cerebral palsy by year and state/territory of birth (1993-2006)

	1993-1994	1995-1997	1998-2000	2001-2003	2004-2006	1993-2006
ACT						
Live Births (LB)	8875	13019	12300	12178	15369	61741
CP Cases	9	7	23	16	12	67
CP cases/1000	1.0	0.5	1.9	1.3	0.8	1.1
NSW						
Live Births (LB)	177331	261600	259035	257505	267314	1222785
CP Cases	111	201	222	239	240	1013
CP cases/1000 LB	0.6	0.8	0.9	0.9	0.9	0.8
NT						
Live Births (LB)	7229	10916	10902	11336	10811	51194
CP Cases	*	13	13	7	5	42
CP cases/1000 LB	0.6	1.2	1.2	0.6	0.5	0.8
QLD						
Live Births (LB)	93356	141218	140198	143791	161785	680348
CP Cases	19	147	174	162	153	655
CP cases/1000 LB	0.2	1.0	1.2	1.1	0.9	1.0
SA						
Live Births (LB)	39519	56986	54782	52917	54136	258340
CP Cases	76	126	108	70	81	461
CP cases/1000 LB	1.9	2.2	2.0	1.3	1.5	1.8
TAS						
Live Births (LB)	13582	19275	18111	16779	17458	85205
CP Cases	6	7	15	24	28	80
CP cases/1000 LB	0.4	0.4	0.8	1.4	1.6	0.9
VIC						
Live Births (LB)	128660	187565	186272	187305	198353	888155
CP Cases	211	351	345	361	321	1589
CP cases/1000 LB	1.6	1.9	1.8	1.9	1.6	1.8
WA						
Live Births (LB)	50395	75729	76125	73871	80573	356693
CP Cases	139	185	212	178	196	910
CP cases/1000 LB	2.8	2.4	2.8	2.4	2.6	2.5
TOTAL pre/perinatal CP cases for Australian Cerebral Palsy Register (1993-2006)						4817

* < 5 cases

Figure 5. Birth prevalence of CP per 1000 live births (LB) by state/territory and year of birth (1993-2006)

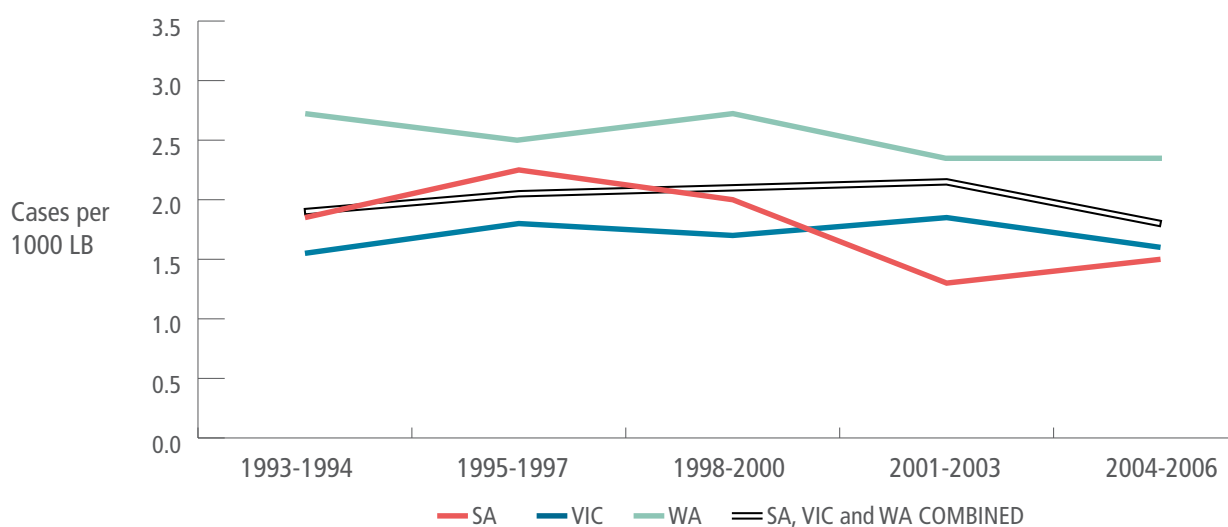


Figure 6. Birth prevalence (95% confidence intervals) of CP per 1000 LB by state/territory (1993-2006)

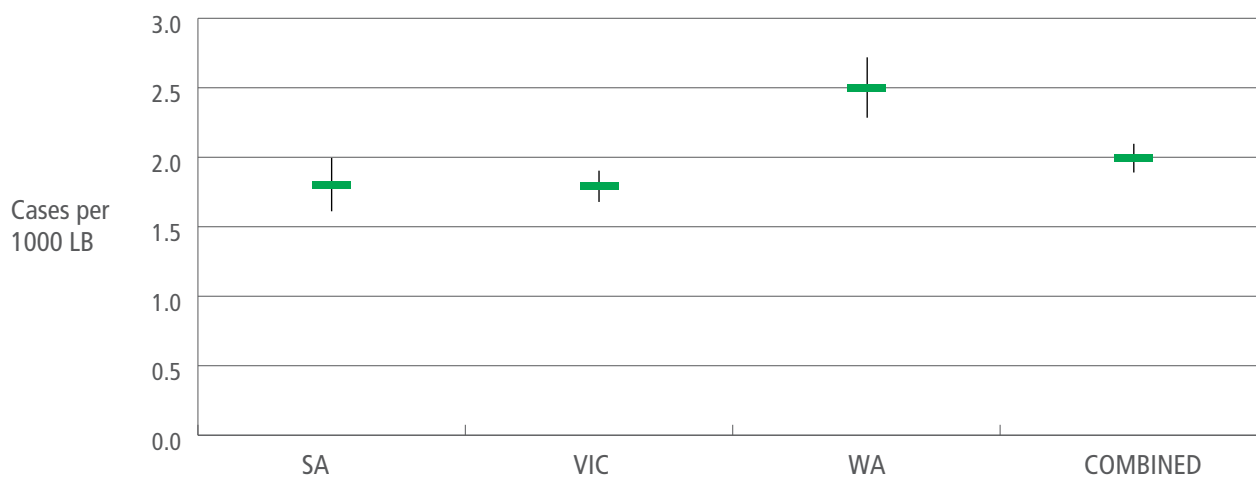


Table 4. Total prevalence of CP per 1000 live births by state/territory (1993-2006), excluding cases with known post-neonatal causes

	CP Cases	Live Births	Prevalence
SA	461	258340	1.8(95%CI 1.6, 2.0)
VIC	1589	888155	1.8(95%CI 1.7,1.9)
WA	910	356693	2.5(95%CI 2.3,2.7)
COMBINED TOTAL	2960	1503188	2.0(95%CI 1.9, 2.1)

In this cohort, three states are considered to be population-based registers (a prevalence of at least 1.5/1000 live births excluding cases where a post-neonatal cause has been identified), with a combined prevalence of 2.0 per 1000 live births (95% CI 1.9 – 2.1). However, it is clear that Western Australia's CP Register reports a higher prevalence of cerebral palsy compared with South Australia and Victoria. The ACPR Group is endeavouring to investigate whether the differences in prevalence across states reflect differences in prevalence or in methodologies.

The most recent 3 year period for the combined cohort shows a statistically non-significant decrease in frequency of cerebral palsy compared with the preceding 3 year period. This is due to a decrease recorded in Victoria, the most populous of the 3 states contributing to the combined estimate. Given the low frequency there is considerable statistical fluctuation in frequency, and a sustained decrease cannot be inferred unless it is maintained over the following triennium.

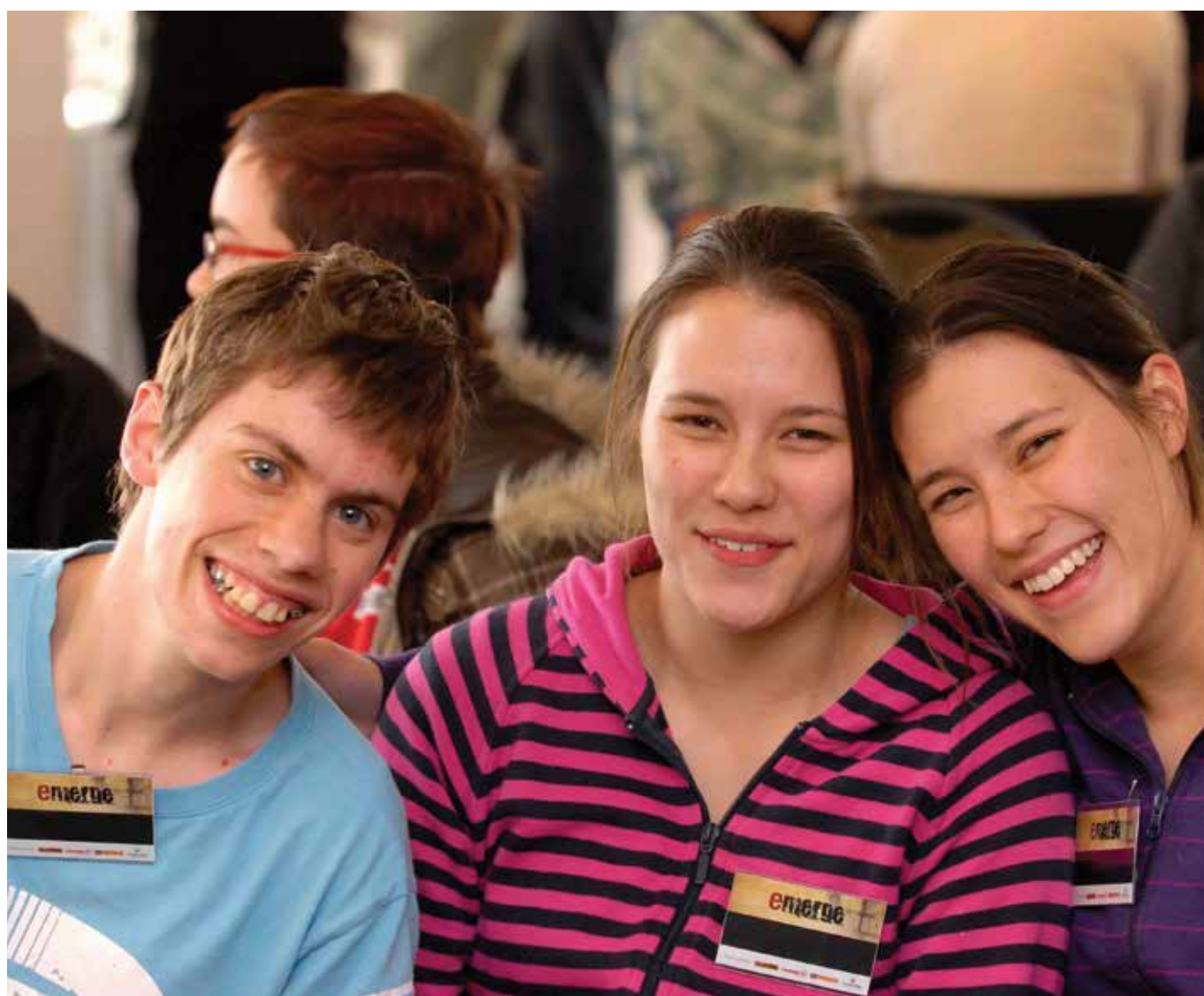
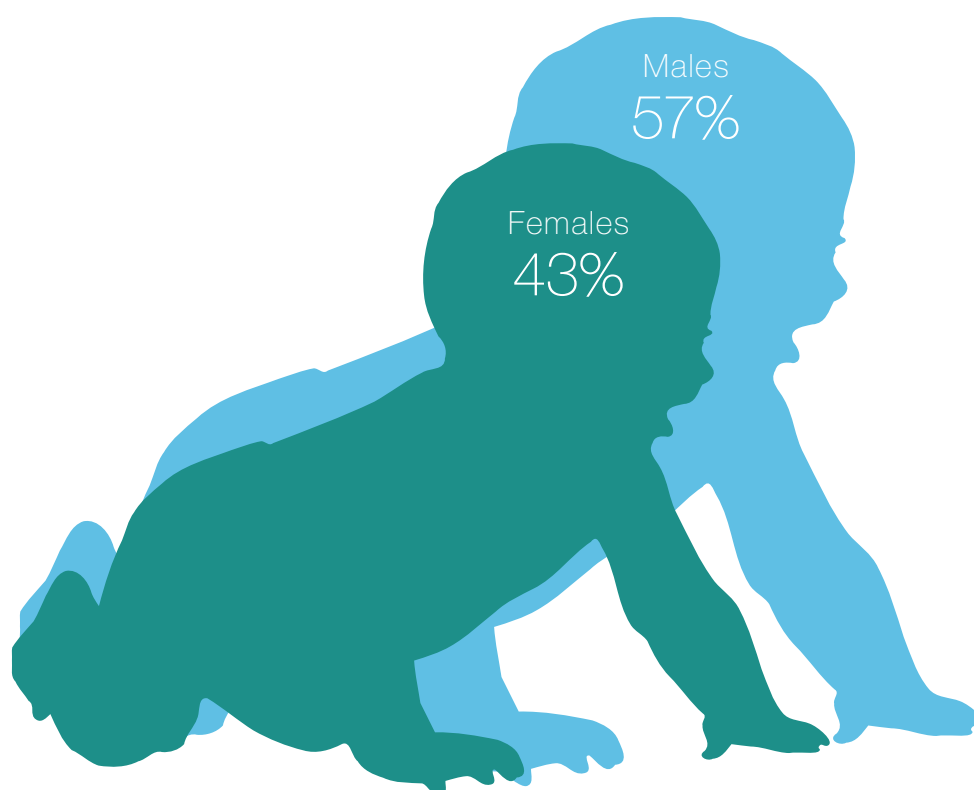


Table 5. Number and percentage of CP cases by sex and state/territory of birth (1993-2006)

	Female n(%)	Male n(%)	TOTAL n
ACT	25 (37.3)	42(62.7)	67
NSW	417(41.2)	596(58.8)	1013
NT	12(28.6)	30(71.4)	42
QLD	280(42.7)	375(57.3)	655
SA	196(42.5)	265(57.5)	461
TAS	24(30.0)	56(70.0)	80
VIC	664(41.8)	925(58.2)	1589
WA	404 (44.4)	506 (55.6)	910
TOTAL	2022	2795	4817
COMBINED SA, VIC, WA	1264 (42.7)	1696(57.3)	2960



Combined data demonstrates proportionally more males (57%) with cerebral palsy, compared to 51% of the Australian population ^[18].

Maternal age at time of delivery

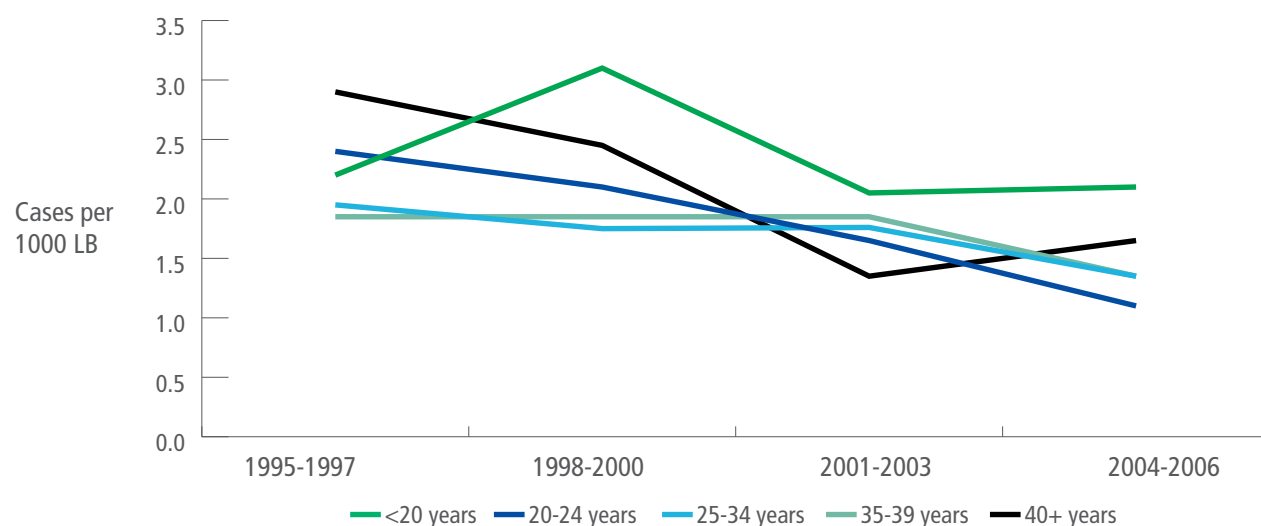
Table 6. Number and percentage of CP cases by maternal age at delivery and state/territory of birth (1993-2006)

	<20	20-24	25-29	30-34	35-39	40+	TOTAL	Unknown
	n(%)^	n(%)^	n(%)^	n(%)^	n(%)^	n(%)^	n	n(%)
ACT	5(7.7)	9(13.8)	14(21.5)	28(43.1)	8(12.3)	*(1.5)	67	2(3.0)
NSW	44(4.7)	154(16.3)	249(26.4)	291(30.8)	168(17.8)	38(4.0)	1013	69(6.8)
NT	*(10.0)	5(16.3)	7(23.3)	10(33.3)	*(10.0)	*(6.7)	42	12(28.6)
QLD	25(5.0)	75(15.1)	148(29.8)	158(31.9)	77(15.5)	13(2.6)	655	159(24.3)
SA	25(5.4)	84(18.2)	134(29.1)	140(30.4)	71(15.4)	7(1.5)	461	*
TAS	*(3.8)	14(17.9)	24(30.8)	23(29.5)	10(12.8)	*(5.1)	80	2(2.5)
VIC	60(4.2)	194(13.6)	411(28.8)	495(34.7)	210(14.7)	55(3.9)	1589	164(10.3)
WA	66(7.9)	137(16.3)	248(29.6)	243(29.0)	126(15.0)	19(2.3)	910	71(7.6)
TOTALS	231	672	1235	1388	673	139	4817	479
COMBINED SA, VIC, WA	151(5.5)	415(15.2)	793(29.1)	878(32.2)	407(14.9)	81(3.0)	2960	235(7.9)

* < 5 cases

(%)^ calculated by $n/(\text{total } n \text{ minus unknown } n)$; provided to allow state/territory comparisons

Figure 7. CP cases per 1000 LB by maternal age at delivery, South Australia, Victoria and Western Australia combined (1995-2006)



The combined distribution of maternal age at delivery in this cohort is comparable to that of the Australian population.

Gestational age at delivery

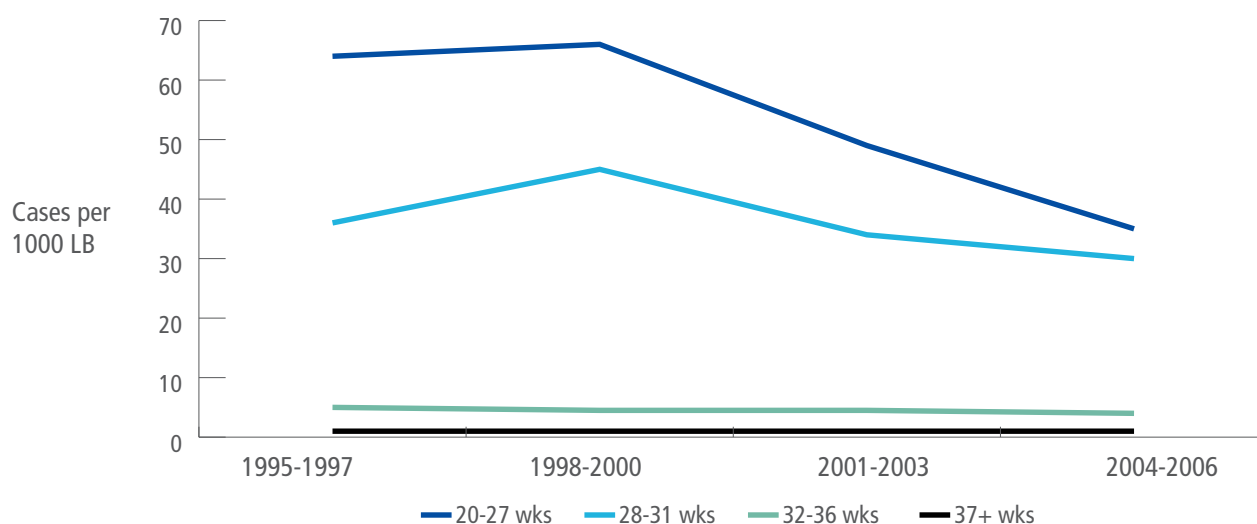
Table 7. Number and percentage of CP cases by gestational age in weeks at delivery and state/territory of birth (1993-2006)

	20-27	28-31	32-36	37-41	>41	TOTAL	Unknown
	n(%)^	n(%)^	n(%)^	n(%)^	n(%)^	n	n(%)
ACT	6(9.1)	13(19.7)	8(12.1)	37(56.1)	*(3.0)	67	*(1.5)
NSW	137(13.8)	124(12.5)	156(15.7)	523(52.8)	51(5.1)	1013	22(2.2)
NT	*(6.1)	*(3.0)	6(18.2)	23(69.7)	*(3.0)	42	9(21.4)
QLD	90(16.3)	100(18.1)	96(17.4)	243(43.9)	24(4.3)	655	102(15.6)
SA	68(14.8)	87(18.9)	74(16.0)	231(50.1)	*(0.2)	461	*
TAS	10(12.5)	10(12.5)	12(15.0)	46(57.5)	*(2.5)	80	*
VIC	201(12.9)	214(13.7)	217(13.9)	903(57.8)	26(1.7)	1589	28(1.8)
WA	102 (11.3)	106 (11.8)	141 (15.6)	530 (58.8)	22 (2.4)	910	9 (1.0)
TOTAL	616	655	710	2536	129	4817	171
COMBINED SA, VIC, WA	371(12.7)	407(13.9)	432(14.8)	1664(56.9)	49(1.7)	2960	37(1.3)

* < 5 cases

(%)^ calculated by $n/(\text{total } n \text{ minus unknown } n)$; provided to allow state/territory comparisons

Figure 8. CP cases per 1000 LB gestational age South Australia, Victoria and Western Australia combined (1995-2006)



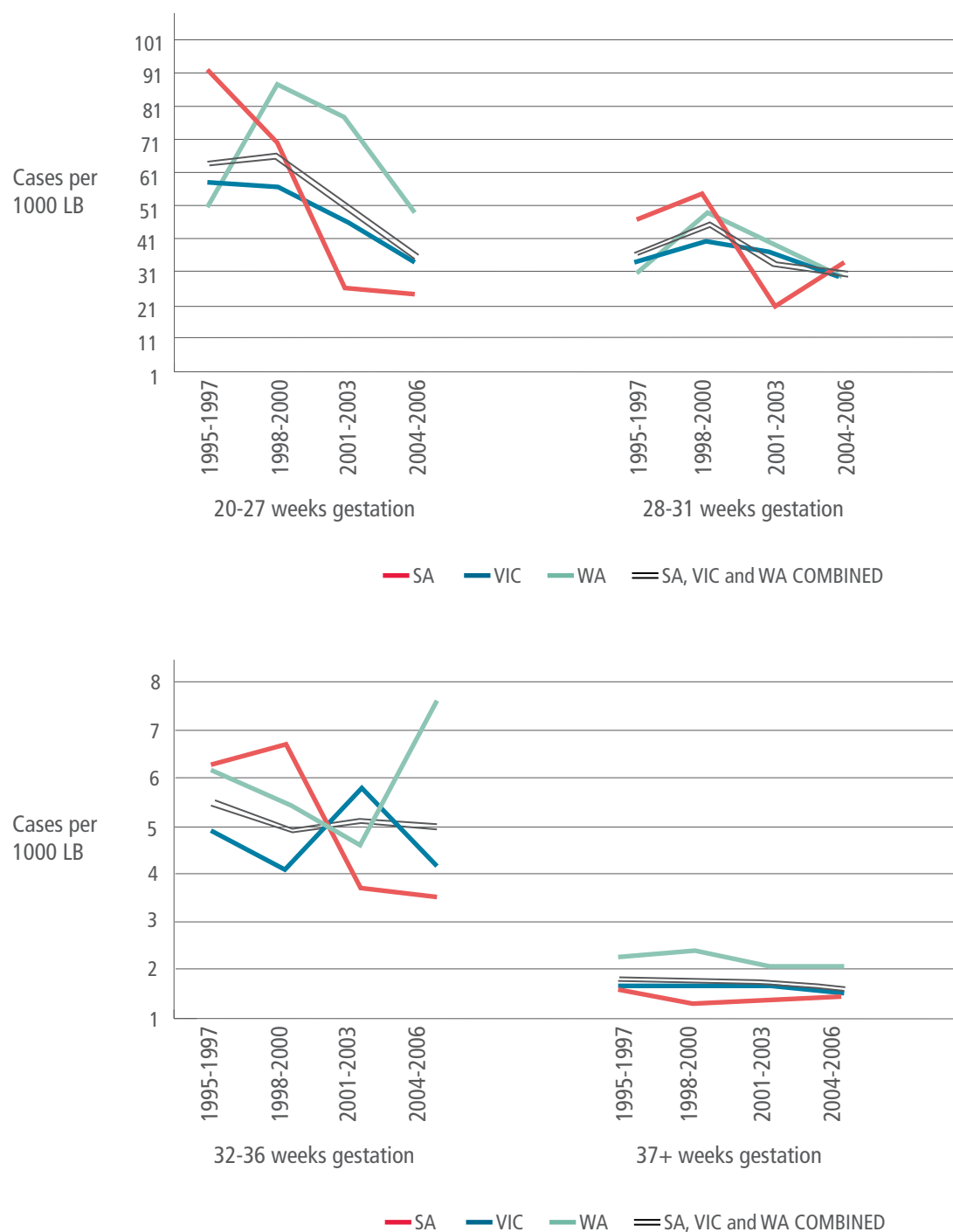
In this cohort the combined data indicates that 41.3% of cerebral palsy births were preterm (< 37weeks gestation) compared with 8.2% of the total population^[18].

Table 8. Number and rate of CP cases by gestational age in weeks at delivery and state/territory of birth (1995-2006)

Weeks gestation	Birth years	SA			VIC			WA		
		n	Live births	Rate/1000LB	n	Live births	Rate/1000LB	n	Live births	Rate/1000LB
20-27	1995-1997	27	296	91.2	44	765	57.5	17	334	50.9
	1998-2000	18	256	70.3	47	826	56.9	25	288	86.8
	2001-2003	7	263	26.6	43	920	46.7	23	296	77.7
	2004-2006	7	291	24.1	33	972	34.0	18	369	48.8
28-31	1995-1997	21	440	47.7	45	1305	34.5	17	552	30.8
	1998-2000	26	478	54.4	54	1328	40.7	29	597	48.6
	2001-2003	9	445	20.2	49	1342	36.5	21	535	39.3
	2004-2006	15	448	33.5	41	1393	29.4	19	647	29.4
32-36	1995-1997	20	3469	5.8	47	10640	4.4	29	5144	5.6
	1998-2000	22	3552	6.2	40	11109	3.6	27	5403	5.0
	2001-2003	11	3414	3.2	60	11348	5.3	22	5391	4.1
	2004-2006	11	3661	3.0	45	12306	3.7	43	6070	7.1
37+	1995-1997	58	52772	1.1	210	174384	1.2	122	69669	1.8
	1998-2000	42	50831	0.8	201	172757	1.2	131	69809	1.9
	2001-2003	43	48792	0.9	203	173759	1.2	107	67617	1.6
	2004-2006	48	49732	1.0	189	183668	1.0	112	73454	1.5
Unknown		9			27			9		



Figure 9. Rate of CP cases per 1000 LB by gestational age and state/territory of birth (1995-2006)



The small number of cases in those born between 20 and 27 weeks results in variation between states. However all three states show a reduction in this gestational age group over at least two time periods when at the same time the survival rate is still increasing steadily. It is important to note that proportions of live births are reported here. Given the high neonatal mortality in those born 20-27 weeks gestation, proportions of CP in neonatal survivors born 20-27 weeks will be higher. For all other gestational age groups the evidence is not yet strong enough to suggest rates are changing.

In term births, 37 weeks and higher, Western Australia has consistently reported a higher rate than South Australia and Victoria. The ACPR Group is endeavouring to investigate whether this difference reflects underascertainment of term born infants in South Australia and Victoria (particularly those that were not admitted to special care or intensive care as newborns) or a higher Western Australian rate of CP in term born infants.



Birth weight

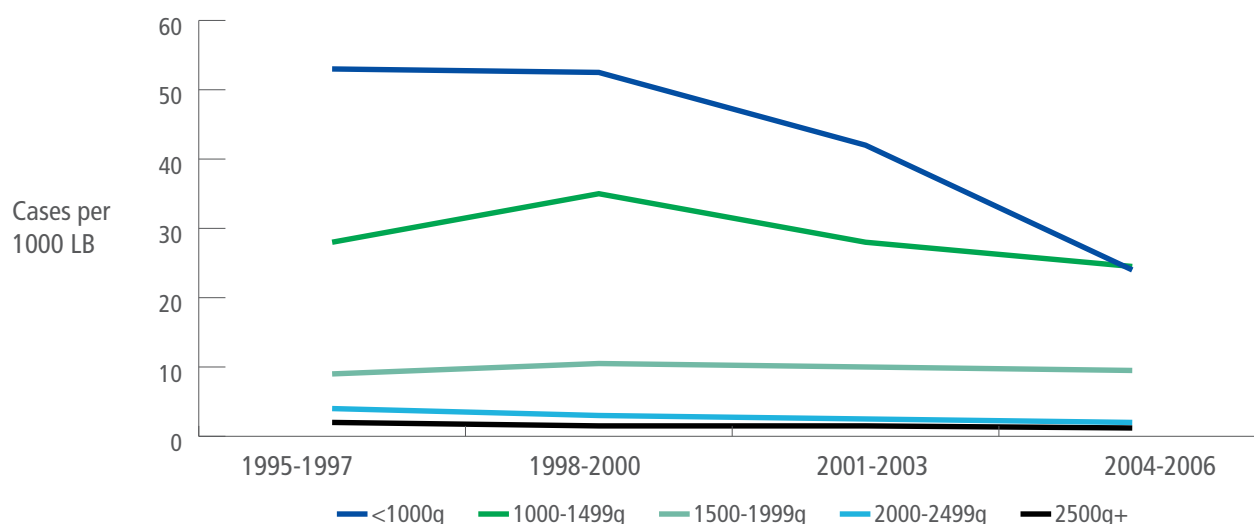
Table 9. Number and percentage of CP cases by birth weight in grams and state/territory of birth (1993-2006)

	<1000	1000-1499	1500-1999	2000-2499	2500-2999	3000-3499	3500-3999	4000-4499	4500+	TOTAL	Unknown
	n(%)^	n(%)^	n(%)^	n(%)^	n(%)^	n(%)^	n(%)^	n(%)^	n(%)^	n	n(%)
ACT	6(9.2)	11(16.9)	6(9.2)	*(4.6)	11(16.9)	15(23.1)	11(16.9)	*(1.5)	*(1.5)	67	*(3.0)
NSW	138(14.1)	120(12.2)	75(7.6)	103(10.5)	135(13.8)	205(20.9)	155(15.8)	37(3.8)	13(1.3)	1013	32(3.2)
NT	*(10.0)	*	*(6.7)	*(6.7)	*(10.0)	13(43.3)	6(20.0)	*(3.3)	*	42	12(28.6)
QLD	75(14.6)	84(16.3)	42(8.2)	60(11.7)	75(14.6)	81(15.8)	66(12.8)	29(5.6)	*(0.4)	655	141(21.5)
SA	65(14.1)	64(13.9)	53(11.5)	36(7.8)	63(13.6)	90(19.5)	57(12.4)	27(5.9)	6(1.3)	461	*
TAS	8(11.3)	7(9.9)	8(11.3)	*(4.2)	10(14.1)	19(26.8)	9(12.7)	7(9.9)	*	80	9(11.3)
VIC	186(12.4)	172(11.4)	146(9.7)	132(8.8)	237(15.8)	301(20.0)	228(15.2)	76(5.1)	25(1.7)	1589	86(5.4)
WA	89(9.8)	95(10.4)	74(8.1)	75(8.2)	154(16.9)	226(24.8)	125(13.7)	34(3.7)	9(1.0)	910	29(3.2)
TOTAL	570	553	406	415	688	950	657	212	56	4817	311
COMBINED SA, VIC, WA	340(12.0)	331(11.6)	273(9.6)	243(8.5)	545(19.2)	617(21.7)	410(14.4)	137(4.8)	40(1.4)	2960	115(3.9)

* < 5 cases

(%)^ calculated by $n/(\text{total } n \text{ minus unknown } n)$; provided to allow state/territory comparisons

Figure 10. CP cases per 1000 LB by birth weight in grams, South Australia, Victoria and Western Australia combined (1993-2006), excluding cases with known post-neonatal causes



Low birth weight is defined as <2500g, very low birth weight <1500g and extremely low birth weight <1000g^[18].

Combined data shows that 41.7% of infants with cerebral palsy were born at a low birth weight compared to 6.4% of the Australian population, 23.4% with very low birth weight compared to 1.1% and 11.8% had an extremely low birth weight compared with 0.5% of the Australian population^[18].

Table 10. Number and percentage of CP cases by birth plurality and state/territory of birth (1993-2006)

Birth Plurality	Singletons	Multiples	TOTAL	Unknown
	n(%)^	n(%)^	n	n(%)
ACT	57(87.7)	8(12.3)	67	*(3.0)
NSW	834(87.5)	119(12.5)	1013	60(5.9)
NT	31(96.9)	*(3.1)	42	10(23.8)
QLD	454(85.0)	80(15.0)	655	121(18.5)
SA	405(87.9)	56(12.1)	461	*
TAS	70(89.7)	10(12.8)	80	*
VIC	1356(87.8)	189(12.2)	1589	44(2.8)
WA	795(89.0)	98(10.9)	910	17(1.8)
TOTAL	4002	561	4817	254
COMBINED SA, VIC	2556(88.2)	343(11.8)	2960	61(2.1)

* < 5 cases

(%)^ calculated by $n/(\text{total } n \text{ minus unknown } n)$; provided to allow state/territory comparisons

Figure 11. Percentage of CP cases by birth plurality and state/territory of birth (1993-2006)



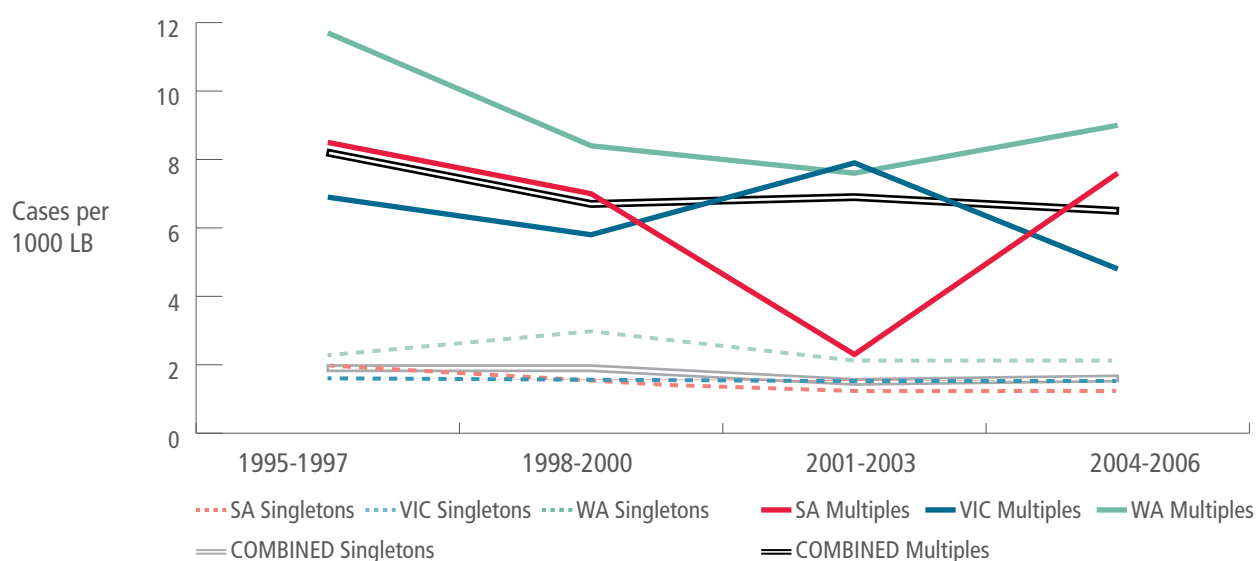
Combined data indicates that 11.9% of those with cerebral palsy were from a multiple birth compared to 3.3% of all births in Australia^[18].

Table 11. CP cases and rate per 1000 live births by plurality and state/territory of birth (1995-2006)

	1995-1997		1998-2000		2001-2003		2004-2006	
	Singletons	Multiples	Singletons	Multiples	Singletons	Multiples	Singletons	Multiples
SA								
CP n	111	15	96	12	66	*	67	13
LB	55222	1764	53031	1752	51107	1807	52426	1706
Rate/1000LB	2.0	8.5	1.8	6.8	1.3	2.2	1.3	7.6
95%CI	1.6-2.4	4.2-12.8	1.4-2.2	3.9-10.7	1.0-1.6	0.0-4.4	1.0-1.6	3.5-11.8
VIC								
CP n	309	38	307	34	299	50	263	35
LB	182029	5570	180077	5976	181014	6376	191181	7172
Rate/1000LB	1.7	6.8	1.7	5.7	1.7	7.8	1.4	4.9
95%CI	1.5-1.9	4.6-9.0	1.5-1.9	3.8-7.6	1.5-1.9	5.6-10	1.2-1.6	3.3-6.5
WA								
CP n	160	25	192	19	151	18	166	23
LB	73534	2195	73846	2279	71472	2399	78085	2488
Rate/1000LB	2.2	11.4	2.6	8.3	2.1	7.5	2.1	9.2
95%CI	1.8-2.5	6.9-15.9	2.2-3.0	4.6-12.1	1.8-2.4	4.0-10.9	1.8-2.4	5.7-13.6
COMBINED SA, VIC, WA								
CP n	580	78	595	65	516	72	496	71
LB	310785	9529	306954	10007	303593	10607	321692	11366
Rate/1000LB	1.9	8.2	1.9	6.5	1.7	6.8	1.5	6.2
95%CI	1.7-2.1	6.4-10	1.7-2.1	4.9-8.1	1.6-1.8	5.2-8.4	1.4-1.6	4.7-7.7

* < 5 cases

Figure 12. CP cases rate per 1000 live births by plurality and state/territory of birth (1995-2006)



There appears to be a declining rate of CP in singletons in South Australia and Victoria but not in Western Australia. The ACPR Group is endeavouring to investigate whether these differences across states reflect a true difference in rates.

Predominant Motor Type

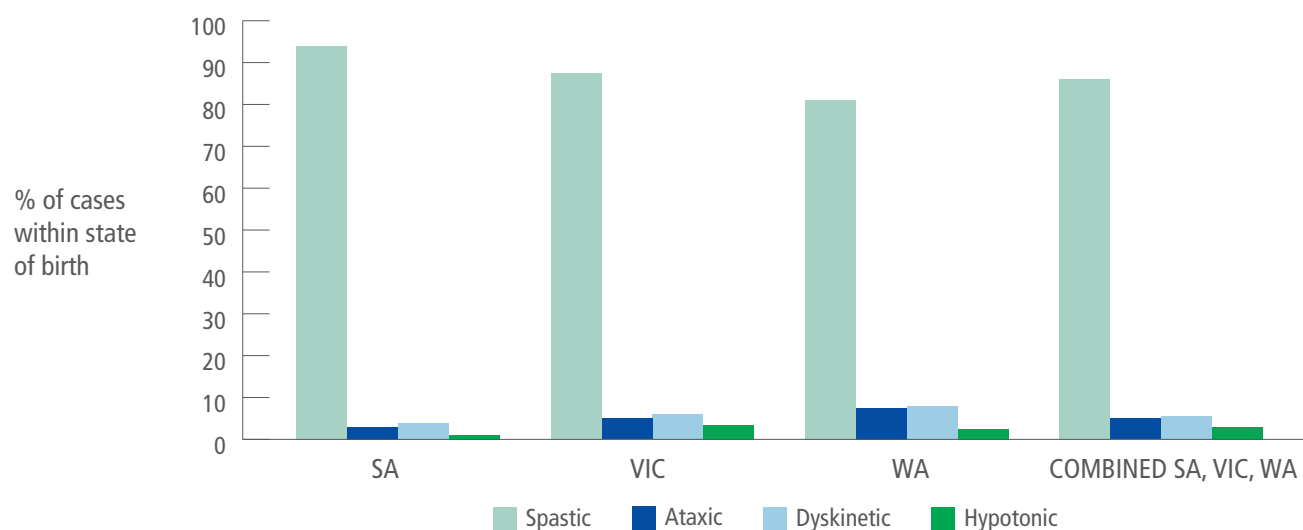
Table 12. Number and percentage of CP cases by predominant motor type and state/territory of birth (1993-2006)

	Spastic n(%)^	Ataxic n(%)^	Dyskinetic n(%)^	Hypotonic n(%)^	TOTAL n	Unknown n(%)
ACT	56(88.9)	*(3.2)	5(7.9)	*	67	*(6.0)
NSW	689(84.1)	47(5.7)	50(6.1)	33(4.0)	1013	194(19.2)
NT	30(85.7)	*(2.9)	*(8.6)	*(2.9)	42	7(16.7)
QLD	474(88.3)	17(3.2)	32(6.0)	14(2.6)	655	118(18.0)
SA	428(94.3)	11(2.4)	14(3.1)	*(0.2)	461	7(1.5)
TAS	48(98.0)	*(2.0)	*	*	80	31(38.8)
VIC	1365(87.6)	72(4.6)	78(5.0)	43(2.8)	1589	31(1.9)
WA	736(80.9)	73(8.0)	80(8.8)	21(2.3)	910	*
TOTAL	3826	224	262	113	4817	392
COMBINED SA, VIC, WA	2529(86.5)	156(5.3)	172(5.9)	65(2.2)	2960	38(1.3)

* < 5 cases

(%)^ calculated by $n/(\text{total } n - \text{unknown } n)$; provided to allow state/territory comparisons

Figure 13. Percentage of CP cases by predominant motor type and state/territory of birth (1993-2006)



In this cohort the combined data indicates that spasticity was the most predominant motor type of cerebral palsy (86.5%). The higher proportion of spasticity in South Australia may reflect the increased proportion of CP cases born very preterm in this state. Victoria and Western Australia have increased proportions of dyskinesia compared to South Australia. The ACPR is endeavouring to determine whether these differences are methodological.

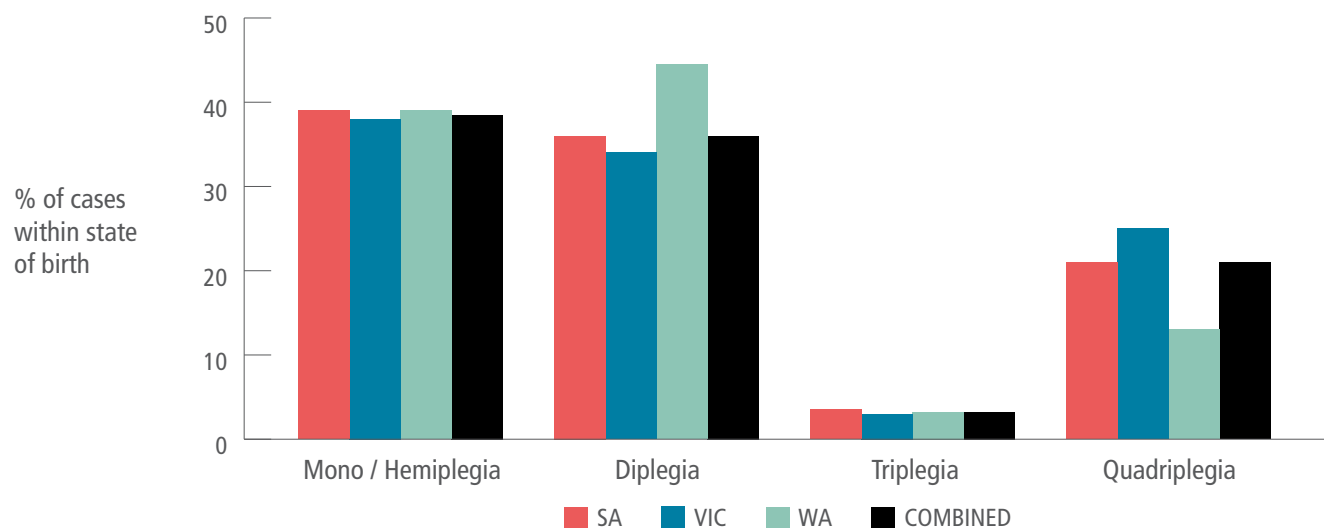
Topographical Pattern of Spasticity

Table 13. Number and percentage of CP cases by topographical pattern of spasticity where spasticity is the predominant motor type and state/territory of birth (1993-2006)

	Monoplegia / Hemiplegia	Diplegia	Triplegia	Quadriplegia	TOTAL
	n(%)	n(%)	n(%)	n(%)	n
ACT	24(42.9)	16(28.6)	*	16(28.6)	56
NSW	274(39.8)	184(26.7)	14(2.0)	217(31.5)	689
NT	9(30.0)	11(36.7)	*	10(33.3)	30
QLD	165(34.8)	181(38.2)	10(2.1)	118(24.9)	474
SA	168(39.2)	157(36.7)	14(3.3)	89(20.8)	428
TAS	14(29.2)	19(39.6)	*(4.2)	13(27.1)	48
VIC	525(38.5)	465(34.0)	35(2.6)	340(24.9)	1365
WA	289(39.3)	327(44.4)	23(3.1)	97(13.2)	736
TOTAL	1468	1360	98	900	3826
COMBINED SA, VIC, WA	982(38.8)	949(37.5)	72(2.8)	526(20.9)	2529

* < 5 cases

Figure 14. Percentage of CP cases by topographical pattern of spasticity where spasticity is the predominant motor type and state/territory of birth (1993-2006)



Combined data indicates that hemiplegia (including monoplegia) or unilateral spastic CP (38.8%) is the most common topographical pattern of spasticity. However if diplegia, triplegia and quadriplegia are grouped as bilateral spastic CP^[18], this pattern is predominant (61.2%).

Gross Motor Function

Table 14. Number and percentage of CP cases by Gross Motor Function Classification System levels (GMFCS) and state/territory of birth (1993-2006)

	I	II	III	IV	V	TOTAL	Unknown	SA Not assessed
	n(%)^	n(%)^	n(%)^	n(%)^	n(%)^	n	n(%)	n(%)
ACT	18(30.0)	15(25.0)	9(15.0)	11(18.3)	7(11.7)	67	7(10.4)	-
NSW	277(34.9)	176(22.2)	90(11.3)	109(13.7)	142(17.9)	1013	219(21.6)	-
NT	10(28.6)	6(17.1)	8(22.9)	*(8.6)	8(22.9)	42	7(16.7)	-
QLD	155(29.9)	120(23.2)	74(14.3)	72(13.9)	97(18.7)	655	137(20.9)	-
SA	184(45.8)	76(18.9)	36(9.0)	49(12.2)	56(13.9)	461	*(0.9)	56(12.1)
TAS	12(41.4)	5(17.2)	*(3.4)	6(20.7)	5(17.2)	80	51(63.8)	-
VIC	518(34.1)	409(26.9)	176(11.6)	193(12.7)	223 (14.7)	1589	70(4.4)	-
WA	156(46.6)	59(17.6)	29(8.7)	34(10.1)	57(17.0)	910	575(63.2)	-
TOTAL	1330	866	423	477	595	4817	1070	56
COMBINED SA, VIC	702(35.5)	485(24.5)	212(10.7)	242(12.2)	279(14.1)	2050	74(3.6)	

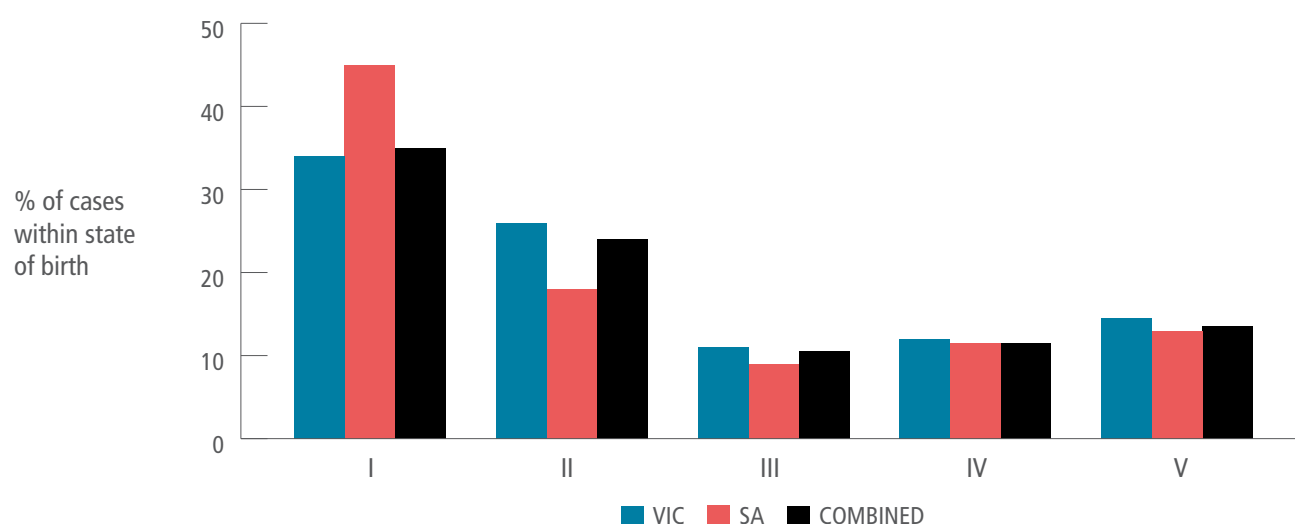
* < 5 cases

SA not assessed: South Australian cases that had not had their follow-up assessment

(%)^ calculated by $n/(\text{total } n \text{ minus unknown } n \text{ and SA } n \text{ not assessed})$; provided to allow state/territory comparisons

Note: An example of the Gross Motor Function Classification System descriptors has been provided in Appendix B

Figure 15. Percentage of CP cases by Gross Motor Function Classification System levels (GMFCS), South Australia and Victoria (1993-2006)



Combined data from Victoria and South Australia indicates that at the age of 5 years the most predominant levels of gross motor function are GMFCS I and II (61.5%). This indicates that more than half the children with cerebral palsy are able to walk indoors and on level surfaces outdoors at age 5 years without needing an assistive mobility device.

Birth defects

Table 15. Number and percentage of CP cases, identified birth defects by state/territory of birth (1993-2006)

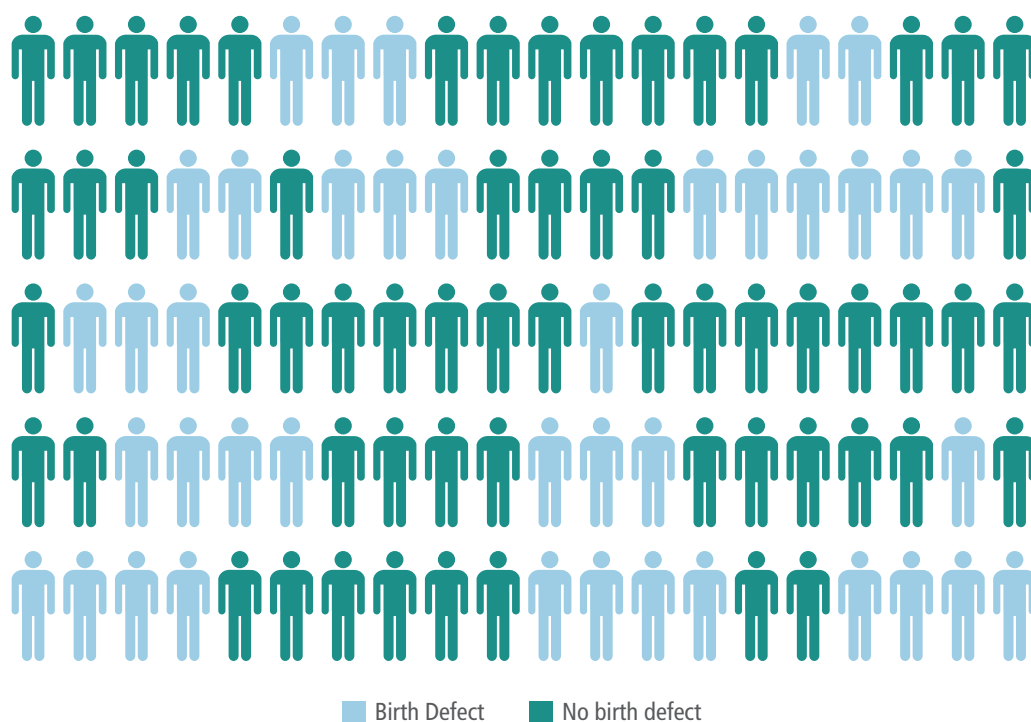
	No known birth defect	One or more birth defects	TOTAL	Unknown
	n(%)^	n(%)^	n	n(%)
ACT	52(82.5)	11(17.5)	67	4(6.0)
NSW	768(82.4)	164(17.6)	1013	81(8.0)
NT	22(84.6)	*(15.4)	42	16(38.1)
QLD	403(77.5)	117(22.5)	655	135(20.6)
SA	276(59.8)	185(40.2)*	461	*
TAS	66(95.7)	*(4.3)	80	11(13.8)
VIC	1311(85.2)	228(14.8)	1589	50(3.1)
WA	731(82.1)	159(17.9)	910	20(2.2)
TOTAL	3629	871	4817	317
COMBINED SA, VIC, WA	2318(80.2)	572(19.8)	2960	70(2.4)

* < 5 cases

(%)^ calculated by $n/(\text{total } n \text{ minus unknown } n)$; provided to allow state/territory comparisons

The SA CP Register is directly linked to SA Birth Defects Register – this figure therefore represents a more likely proportion of children with cerebral palsy who have a birth defect.

Figure 16. Percentage of CP cases with one or more identified birth defects, South Australia (1993-2006)



Combined data indicates that $\approx 20\%$ of children with cerebral palsy also had an identified birth defect. This figure is likely to be as high as 40% (Figure 16), compared with the Australian population figures of 4.3-5.5%^[19-21].

ASSOCIATED IMPAIRMENTS

Vision

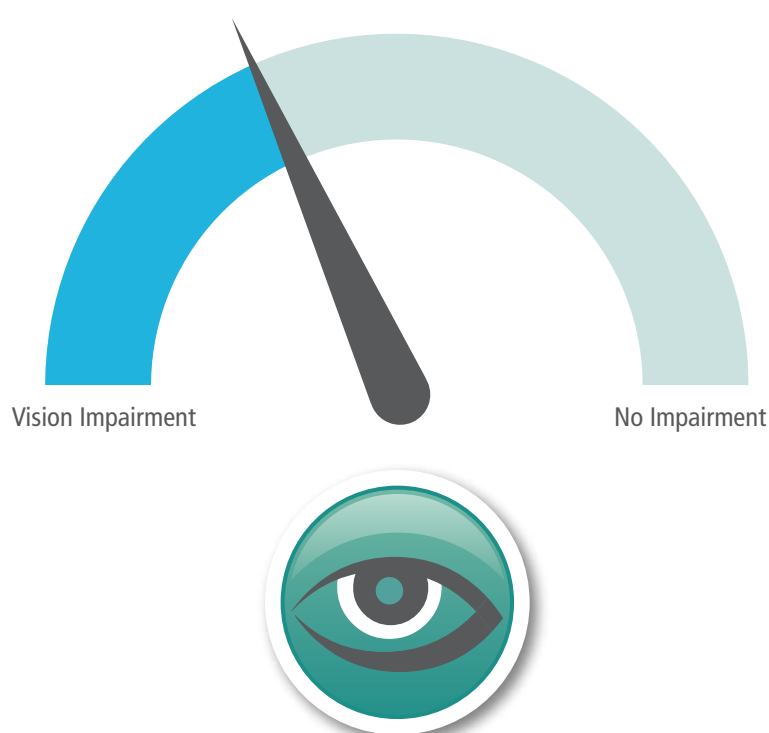
Table 16. Number and percentage of CP cases by vision status and state/territory of birth (1993-2006)

	No impairment n(%)^	Some impairment n(%)^	Functionally blind n(%)^	TOTAL n	Unknown n(%)	SA Not assessed n(%)
ACT	38(64.4)	19(32.2)	*(3.4)	67	8(11.9)	
NSW	560(64.1)	280(32.0)	34(3.9)	1013	139(13.7)	
NT	15(42.9)	14(40.0)	6(17.1)	42	7(16.7)	
QLD	291(59.4)	166(33.9)	33(6.7)	655	165(25.2)	
SA	190(60.1)	112(35.4)	14(4.4)	461	34(7.4)	111(24.1)
TAS	55(77.5)	14(19.7)	*(2.8)	80	9(11.3)	
VIC	759(52.2)	633(43.6)	61(4.2)	1589	136(8.5)	
WA	605(68.8)	223(25.3)	52(5.9)	910	30(3.3)	
TOTAL	2513	1666	204	4817	192	111
COMBINED SA, VIC, WA	1554(58.7)	968(36.5)	127(4.8)	2960	200(2.3)	111

* < 5 cases

SA not assessed: South Australian cases who had not had their follow-up assessment at time of reporting

(%)^ calculated by $n/(\text{total } n \text{ minus unknown } n \text{ and SA } n \text{ not assessed})$; provided to allow state/territory comparisons



Hearing

Table 17. Number and percentage of CP cases by hearing status and state/territory of birth (1993-2006)

	No impairment n(%)^	Some impairment n(%)^	Bilateral deafness n(%)^	TOTAL n	Unknown n(%)	SA Not assessed n(%)
ACT	56(90.3)	5(8.1)	*(1.6)	67	5(7.5)	
NSW	842(88.7)	69(7.3)	38(4.0)	1013	64(6.3)	
NT	29(87.9)	*(9.1)	*(3.0)	42	9(21.4)	
QLD	459(87.8)	50(9.6)	14(2.7)	655	132(20.2)	
SA	313(91.8)	19(5.6)	9(2.6)	461	12(2.6)	108(23.4)
TAS	73(96.1)	3(3.9)	*	80	*(5.0)	
VIC	1269(87.3)	143(9.8)	41(2.8)	1589	136(8.6)	
WA	801(92.0)	55(6.3)	15(1.7)	910	39(4.3)	
TOTAL	3842	347	119	4817	401	108
COMBINED SA, VIC, WA	2383(89.4)	217(8.1)	65(2.4)	2960	187(6.3)	108

* < 5 cases

SA not assessed: South Australian cases who had not had their follow-up assessment at time of reporting

(%)^ calculated by $n/(\text{total } n \text{ minus unknown } n \text{ and SA } n \text{ not assessed})$; provided to allow state/territory comparisons

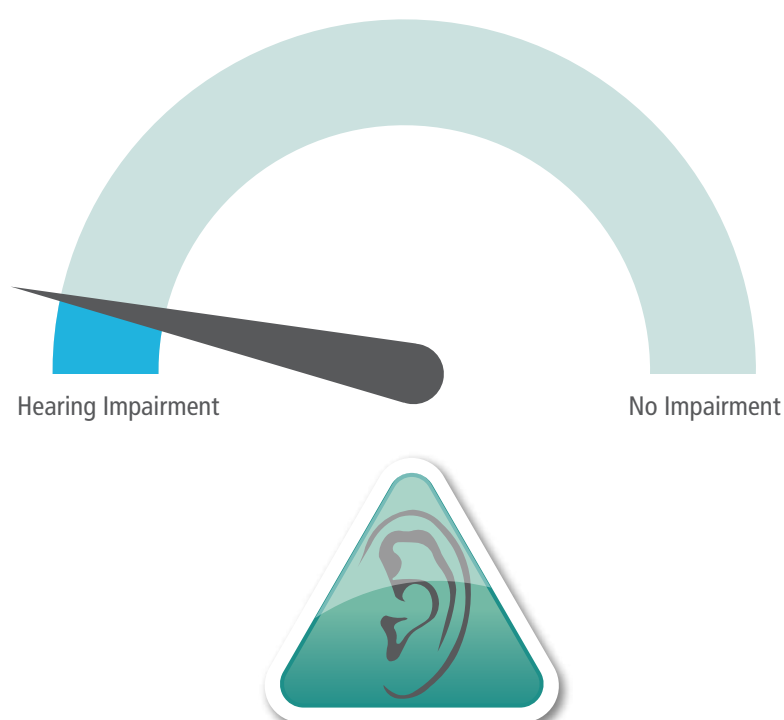


Table 18. Number and percentage of CP cases by speech status and state/territory of birth (1993-2006)

	No impairment n(%)^	Some impairment n(%)^	Non-verbal n(%)^	TOTAL n	Unknown n(%)	SA Not assessed n(%)
ACT	27(41.5)	28(43.1)	10(15.4)	67	*(3.0)	
NSW	335(35.4)	397(41.9)	215(22.7)	1013	66(6.5)	
NT	14(42.4)	6(18.2)	13(39.4)	42	9(21.4)	
QLD	207(39.7)	191(36.7)	123(23.6)	655	134(20.5)	
SA	167(48.0)	135(38.8)	46(13.2)	461	*(0.7)	110(23.9)
TAS	42(55.3)	26(34.2)	8(10.5)	80	*(5.0)	
VIC	580(40.2)	474(32.8)	390(27.0)	1589	145(9.1)	
WA	335(39.0)	308(35.9)	215(25.1)	910	52(5.7)	
TOTAL	1707	1565	1020	4817	415	110
COMBINED SA, VIC, WA	1082(40.1)	917(34.6)	651(24.5)	2960	200(7.0)	110

* < 5 cases

SA not assessed: South Australian cases who had not had their follow-up assessment at time of reporting

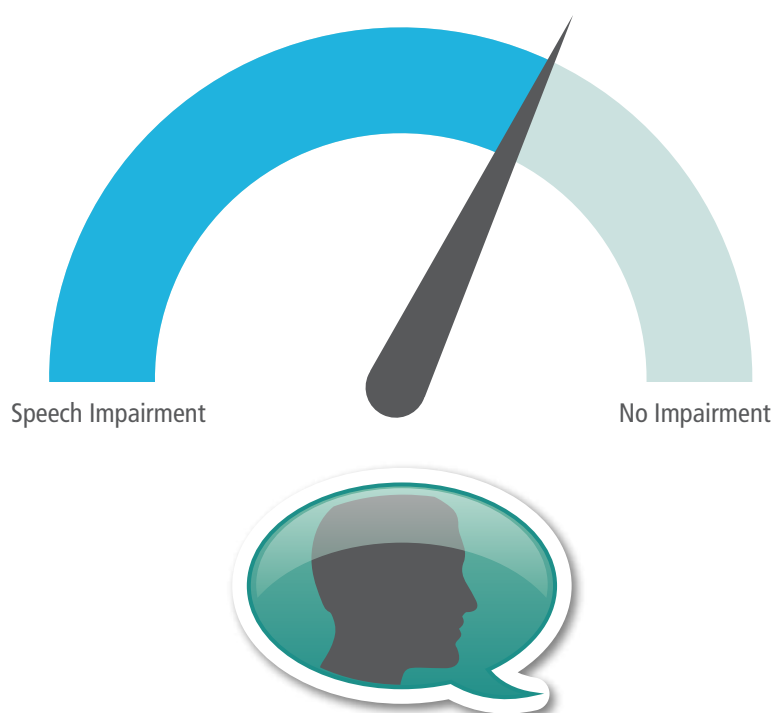
(%)^ calculated by $n/(\text{total } n \text{ minus unknown } n \text{ and SA } n \text{ not assessed})$; provided to allow state/territory comparisons

Table 19. Number and percentage of CP cases by presence/absence of epilepsy** and state/territory of birth (1993-2006)

	No Epilepsy	Resolved#	Epilepsy	TOTAL	Unknown	SA Not assessed
	n(%)^	n(%)^	n(%)^	n	n(%)	n(%)
ACT	49(76.6)	*(3.1)	13(20.3)	67	*(4.5)	
NSW	682(70.7)	49(5.1)	233(24.2)	1013	49(4.8)	
NT	17(44.7)	*(2.6)	20(52.6)	42	*(9.5)	
QLD	351(64.8)	21(3.9)	170(31.4)	655	113(17.3)	
SA	231(70.6)	19(5.8)	77(23.5)	461	28(6.1)	106(23.0)
TAS	56(72.7)	8(10.4)	13(16.9)	80	*(3.8)	
VIC	1074(69.6)	17(1.1)	451(29.2)	1589	47(3.0)	
WA	606(68.1)	13 (1.5)	271(30.4)	910	20 (2.2)	
TOTAL	3066	130	1248	4817	267	
COMBINED VIC, WA	1911(69.2)	49(1.8)	799(28.9)	2960	95(3.3)	106

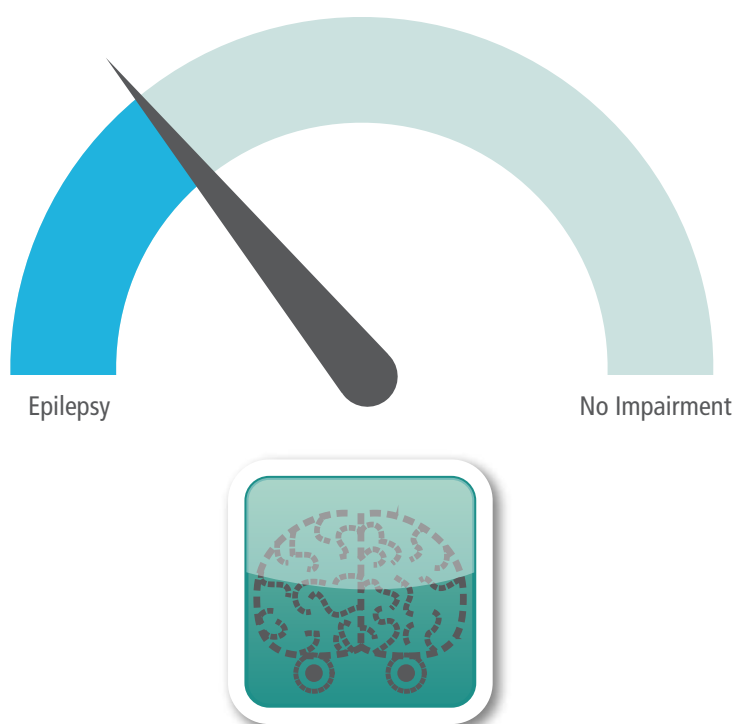
* < 5 cases

Resolved # = Resolved by 5 years of age (seizure free for two or more years without medication)

**Epilepsy is defined as two or more afebrile seizures before age 5 years; does not include neonatal seizures.

SA not assessed: South Australian cases that had not had their follow-up assessment at time of reporting

(%)^ calculated by $n/(\text{total } n \text{ minus unknown } n \text{ and SA } n \text{ not assessed})$; provided to allow state/territory comparisons



Intellectual impairment

Table 20. Number and percentage of CP cases by level of intellectual impairment and state/territory of birth (1993-2006)

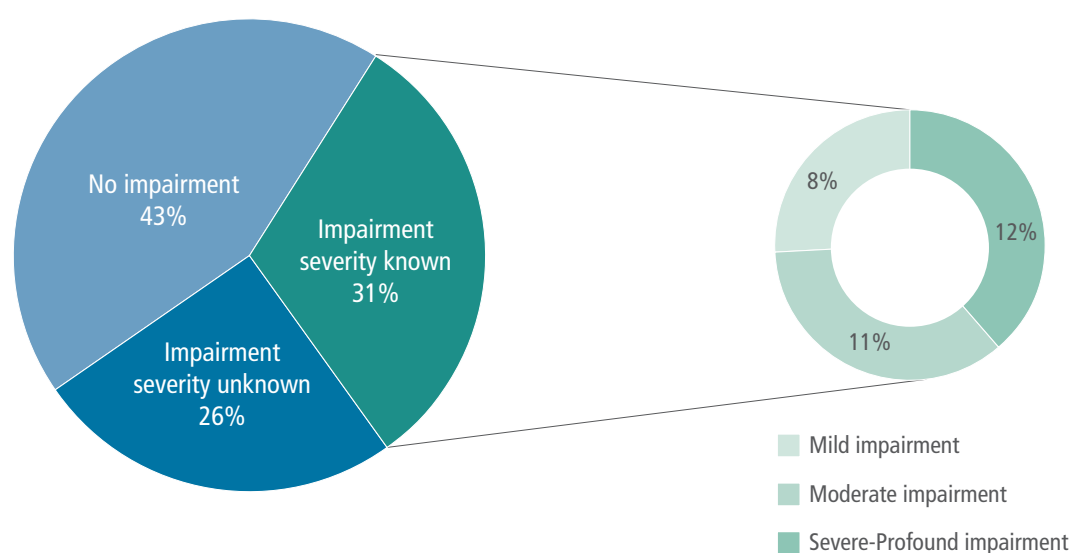
	No impairment n (%) ^	Unconfirmed Probably borderline or no impairment n (%)^	Unconfirmed Probably greater than borderline impairment, severity uncertain n (%)^	Mild impairment n (%)^	Moderate impairment n (%)^	Severe- profound impairment n (%)^	TOTAL n	Unknown n (%)	SA Not assessed n (%)
ACT	23(38.3)	8(13.3)	11(18.3)	7(11.7)	7(11.7)	*(6.7)	67	7(10.4)	
NSW	334(36.7)	105(11.5)	105(11.5)	124(13.6)	128(14.1)	114(12.5)	1013	103(10.2)	
NT	14(41.2)	*(2.9)	8(23.5)	*(5.9)	*(8.8)	6(17.6)	42	8(19.0)	
QLD	185(37.0)	69(13.8)	75(15.0)	52(10.4)	61(12.2)	58(11.9)	655	155(23.7)	
SA	184(56.2)	28(8.5)	13(4.0)	47(14.4)	26(8.0)	29(8.9)	461	24(5.2)	110(23.9)
TAS	42(57.5)	*(5.5)	*(2.7)	10(13.7)	12(16.4)	*(4.1)	80	7(8.8)	
VIC	431(30.5)	322(22.8)	217(15.4)	163(11.5)	117(8.3)	163(11.5)	1589	176(11.1)	
WA	510(57.6)	10(1.1)	89(10.0)	73(8.2)	79(8.9)	125(14.1)	910	24(2.6)	
TOTAL	1723	5547	520	478	433	502	4817	504	110
COMBINED SA, VIC, WA	1125(42.8)	360(13.7)	319(12.1)	283(10.8)	222(8.5)	317(12.1)	2960	224(7.6)	110

* < 5 cases

SA not assessed: South Australian cases who had not had their follow-up assessment at time of reporting

(%)^ calculated by $n/(\text{total } n \text{ minus unknown } n \text{ and SA } n \text{ not assessed})$; provided to allow state/territory comparisons

Figure 17. Percentage of CP cases by level of intellectual impairment and state/territory of birth (1993-2006), South Australia, Victoria and Western Australia combined



Combined data indicates that associated impairments were common for children with cerebral palsy. At the age of five: 30% had epilepsy; >50% had intellectual impairment; 60% had speech impairment; 40% had vision impairment and 10% had hearing impairment.



Prevalence

Table 21. CP cases by identified post-neonatal (PNN) cause and state/territory of birth (1993-2006)

	PNN acquired cases	% of all CP cases	Live births	Rate of PNN cases per 10,000 live births	95% CI
ACT	10	13.0	61741	(1.6)	
NSW	117	10.4	1222785	(1.0)	
NT	10	19.2	51194	(2.0)	
QLD	29	4.2	680348	(0.4)	
SA	15	3.2	258340	0.6	0.3-0.9
TAS	*	2.4	85205	(0.2)	
VIC	90	5.6	888155	1.0	0.8-1.2
WA	70	7.1	356693	2.0	1.5-2.5
COMBINED SA, VIC, WA	175	5.6	1503391	1.2	0.6-2.6

* < 5 cases

In this cohort the combined data indicates the prevalence for post-neonatally acquired CP was estimated to be 1.2 per 10,000 live births.

Post-neonatal cause

Table 22. Number and percentage of CP cases by identified post-neonatal cause, born in South Australia, Victoria and Western Australia combined (1993-2006)

Post-Neonatal Cause	TOTAL CASES SA, VIC and WA n(%)
Viral/bacterial infection unspecified	46(26.3)
CVA# associated with surgery	13(7.4)
CVA# associated with cardiac complications	9(5.1)
Spontaneous/other CVA#	38(21.7)
Fall	*(2.3)
Non-accidental injury	22(12.6)
Other head injury	*(0.6)
Near drowning	5(2.9)
Apparent life threatening event	5(2.9)
Post-immunisation	*(1.1)
Post-seizure	7(4.0)
Peri-operative hypoxia	*(1.7)
Other post-natal event	13(7.4)
Motor vehicle accident	7(4.0)
TOTAL	175

* < 5 cases CVA# Cerebro-vascular accident

Combined data indicates the predominant post-neonatal cause of cerebral palsy is a CVA being either spontaneous, associated with surgery or with cardiac complications.

Sex

Table 23. Number and percentage of CP cases by sex and state/territory of birth (1993-2006)

	Female n(%)	Male n(%)	TOTAL n
SA	6(40.0)	9(60.0)	15
VIC	39(43.3)	51(56.7)	90
WA	31(44.3)	39(55.7)	70
COMBINED SA, VIC, WA	76(43.4)	99(56.6)	175

* < 5 cases



Combined data demonstrates that males are at a higher risk of developing cerebral palsy. 56% of the cohort of cases due to post-neonatal causes was male compared to 51% of the Australian population.¹⁸

Maternal age at time of delivery

Table 24. Number and percentage of CP cases by maternal age group in years at delivery, South Australia, Victoria and Western Australia combined (1993-2006).

	<20 n(%)^	20-24 n(%)^	25-29 n(%)^	30-34 n(%)^	35-39 n(%)^	40+ n(%)^	TOTAL n	Unknown n(%)
COMBINED SA, VIC, WA	19(12.2)	39(25.0)	37(23.7)	36(23.1)	22(14.1)	3(1.9)	175	19(10.9)

* < 5 cases

(%)^ calculated by $n/\text{total } n$ minus **unknown n**; provided to allow state/territory comparisons

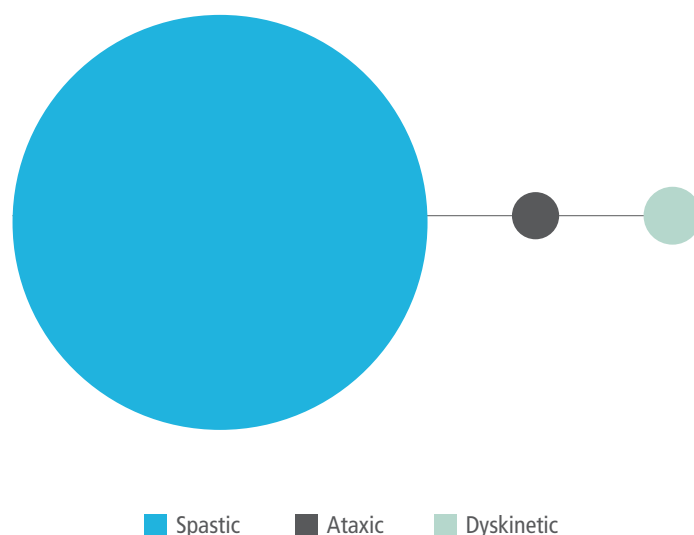
Predominant Motor Type

Table 25. Number and percentage of CP cases by predominant motor type, South Australia, Victoria and Western Australia combined (1993-2006)

	Spastic n(%)^	Ataxic n(%)^	Dyskinetic n(%)^	Hypotonic n(%)^	TOTAL n	Unknown n(%)
COMBINED SA, VIC, WA	160(91.4)	6(3.4)	7(4.0)	* (1.1)	175	*

* < 5 cases

(%)^ calculated by $n/(\text{total } n \text{ minus unknown } n)$; provided to allow state/territory comparisons



Topography

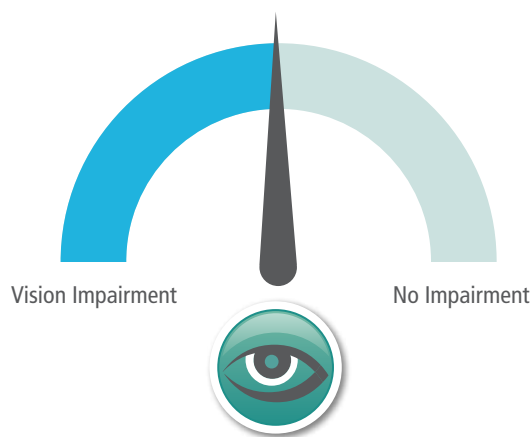
Table 26. Number and percentage of CP cases by topographical pattern of spasticity where spasticity is the predominant motor type, South Australia, Victoria and Western Australia combined (1993-2006)

	Monoplegia / Hemiplegia n(%)	Diplegia n(%)	Triplegia n(%)	Quadriplegia n(%)	TOTAL n
COMBINED SA, VIC, WA	88(55.0)	18(11.3)	6(3.8)	48(30.0)	160

* < 5 cases

In this cohort the combined data indicates that spasticity was the most predominant motor type of cerebral palsy (91.4%) and hemiplegia (including monoplegia) or unilateral spastic CP (55%) is the most common topographical pattern of spasticity.

ASSOCIATED IMPAIRMENTS



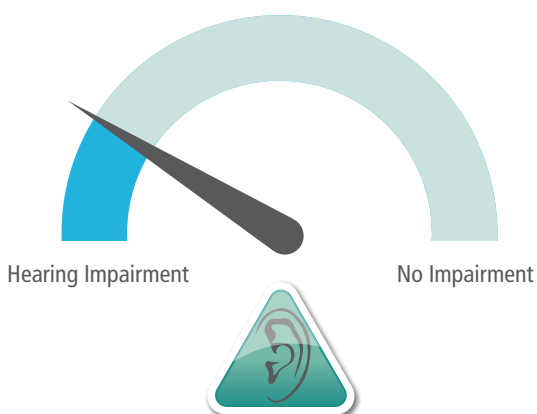
Vision

Table 27. Number and percentage of CP cases by vision status, South Australia, Victoria and Western Australia combined (1993-2006)

	No impairment n(%)^	Some impairment n(%)^	Functionally blind n(%)^	TOTAL n	Unknown n(%)
COMBINED SA,VIC,WA	80(51.3)	57(36.5)	19(12.2)	175	19(10.9)

* < 5 cases

(%)^ calculated by $n/(\text{total } n \text{ minus unknown } n)$



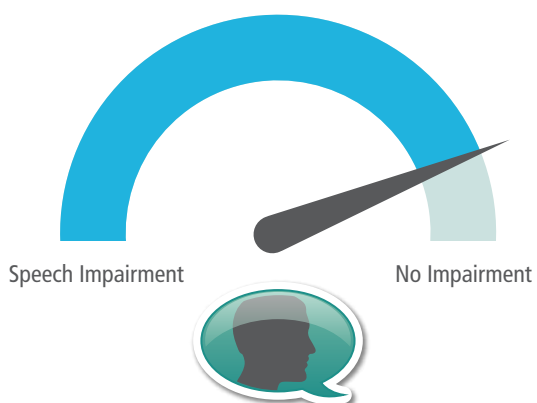
Hearing

Table 28. Number and percentage of CP cases by hearing status, South Australia, Victoria and Western Australia combined (1993-2006)

	No impairment n(%)^	Some impairment n(%)^	Bilateral deafness n(%)^	TOTAL n	Unknown n(%)
COMBINED SA, VIC, WA	141(88.7)	11(6.9)	7(4.4)	175	16(9.1)

* < 5 cases

(%)^ calculated by $n/(\text{total } n \text{ minus unknown } n)$



Speech

Table 29. Number and percentage of CP cases by speech status, Victoria and Western Australia combined (1993-2006)

	No impairment n(%)^	Some impairment n(%)^	Non-verbal n(%)^	TOTAL n	Unknown n(%)
COMBINED VIC, WA	30(20.3)	65(43.9)	53(35.8)	160	12(7.5)

NB: SA data not included

* < 5 cases

(%)^ calculated by $n/(\text{total } n \text{ minus unknown } n)$

Epilepsy

Table 30. Number and percentage of CP cases by presence/absence of epilepsy**, South Australia, Victoria and Western Australia combined (1993-2006)

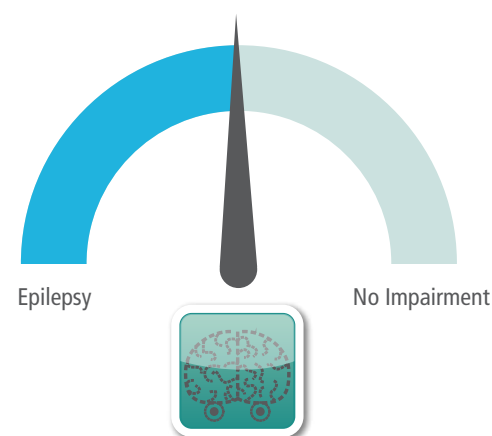
	No Epilepsy	Resolved#	Epilepsy	TOTAL	Unknown
	n(%)^	n(%)^	n(%)^	n	n(%)
COMBINED SA,VIC, WA	68(39.8)	12(7.0)	91(53.2)	175	4(2.3)

* < 5 cases

Resolved # = Resolved by 5 years of age (seizure free for two or more years without medication)

**Epilepsy is defined as two or more afebrile seizures before age 5 years; does not include neonatal seizures.

(%)^ calculated by $n/(\text{total } n \text{ minus unknown } n)$;



Intellectual impairment

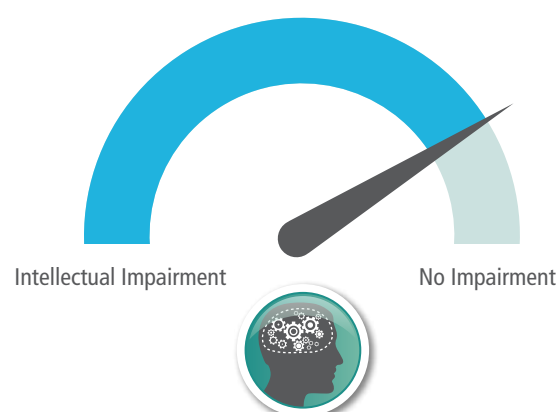
Table 31. Number and percentage of CP cases by level of intellectual impairment, Victoria and Western Australia combined (1993-2006)

	No impairment	Unconfirmed Probably borderline or no impairment	Unconfirmed Probably greater than borderline impairment, severity uncertain	Mild impairment	Moderate impairment	Severe-profound impairment	TOTAL	Unknown
	n(%) ^	n(%)^	n(%)^	n(%)^	n(%)^	n(%)^	n	n(%)
COMBINED VIC,WA	42(29.2)	16(11.1)	30(20.8)	15(10.4)	15(10.4)	26(18.1)	160	16(10.0)

NB: SA data not included

* < 5 cases

(%)^ calculated by $n/(\text{total } n \text{ minus unknown } n)$;



Combined data indicates that associated impairments were common for children with cerebral palsy. At the age of five: 50% had epilepsy; >50% had intellectual impairment; 80% had speech impairment; 50% had vision impairment and 20% had hearing impairment.

APPENDIX A

Information and contact details of the contributing State and Territory CP Registers

Name	Date of Establishment	Custodian Organisation	Type of Consent Required	Contactable for Future Research
NSW and ACT Cerebral Palsy Register	2005	Cerebral Palsy Alliance Research Institute, a wholly owned subsidiary of Cerebral Palsy Alliance	IC	Yes
Northern Territory Cerebral Palsy Register	2008	Centre for Disease Control	IC	Yes
Queensland Cerebral Palsy Register	2006	Cerebral Palsy League and Queensland Health	IC	90%
The South Australian Cerebral Palsy Register	1998	Women's and Children's Health Network	L, IC	Yes
Tasmanian Cerebral Palsy Register	2008	Cerebral Palsy Alliance Research Institute, a wholly owned subsidiary of Cerebral Palsy Alliance in collaboration with St Giles	IC	Yes
Victorian Cerebral Palsy Register	1986	Murdoch Childrens Research Institute, Royal Children's Hospital, Melbourne	E, IC,O	Yes (Approximately 80%)
Western Australian Register of Developmental Anomalies - Cerebral Palsy	1977	Department of Health WA	E, O	No

IC Registration after gaining individual consent, L Legislation allowing collection of data, E Ethics approval to collect data without informed consent, O Other e.g. combination or alternative

New South Wales and Australian Capital Territory Cerebral Palsy Registers

CEREBRAL PALSY ALLIANCE RESEARCH INSTITUTE,
A WHOLLY OWNED SUBSIDIARY OF CEREBRAL PALSY ALLIANCE

Target population:

Individuals who have acquired cerebral palsy before age 5 years who were born or currently live in New South Wales or the Australian Capital Territory

Sarah McIntyre

Cerebral Palsy Alliance Research Institute

187 Allambie Rd
Allambie Heights,
NSW 2100, Australia
smcintyre@cerebralpalsy.org.au
(02) 9479 7200

Purpose:

The main aims of the CP Register are to monitor incidence and prevalence of cerebral palsy, gain further understanding about the causes of cerebral palsy, evaluate preventive strategies and assist in planning services for children and adults who have cerebral palsy. These goals represent the aims of the NSW and ACT CP Register and are aligned with this register's partnership with the Australian Cerebral Palsy Register.

We are moving into an era where prevention of secondary impairments has become a particularly high priority for the NSW CP Register and CP Alliance due to the resounding success of a follow-up program for CP, called CPUP, which was initiated in Sweden in 1994. This program has reduced the incidence of hip dislocation, pain, scoliosis and contractures in a total population of children with CP. We have formed a collaboration with researchers from this group and our research question is 'CP Check-Up: Can a surveillance program achieve similar reductions in secondary impairment in an Australian context?'

An extension to the CP Register has been built and will provide a platform for collection of surveillance data in NSW. This platform will eventually be made available Australia-wide. For further information please contact lead Research Project Officer, Petra Karlsson at cpregister@cerebralpalsy.org.au

Northern Territory Cerebral Palsy Register

DEPARTMENT OF HEALTH AND FAMILIES

Target population:

All individuals who have cerebral palsy, who were born in, or live in, the Northern Territory

Jennifer Fry and Dr Keith Edwards

Centre for Disease Control

Building 4, Royal Darwin Hospital
NT 0811 Australia
cp.register@nt.gov.au
(08) 8922 8044

Purpose:

The main aims of the CP register are to determine the number, location and abilities of people in the Northern Territory who have cerebral palsy; also to use this information to assist in the planning, development and provision of services, and to provide a resource for research into cerebral palsy.

Queensland Cerebral Palsy Register

CEREBRAL PALSY LEAGUE OF QUEENSLAND

Target population:

All people who were born in or receive services in Queensland who have CP

Michael deLacy

QCPR

PO Box 386

Fortitude Valley

Brisbane

Qld 4006 Australia

mdelacy@cplqld.org.au

(07) 3358 8002

Purpose:

To determine the number, locations and general abilities of the population of people with CP in QLD for use by government, non-government agencies and people with cerebral palsy in service planning; provide a population resource for intervention trials; contribute to investigations into causes and prevention of CP.

The South Australian Cerebral Palsy Register (part of the South Australian Birth Defects Register)

WOMEN'S AND CHILDREN'S HEALTH NETWORK

Target population:

All children who live in or were born in South Australia who have been diagnosed with CP, including post-neonatally acquired CP up to 2 years of age.

Catherine Gibson and Heather Scott

Women's and Children's Health Network

72 King William Road

North Adelaide

Adelaide

SA 5006 Australia

sabdr@health.sa.gov.au

(08) 8161 7368

Purpose:

The main aims of the South Australian Cerebral Palsy Register are to:

- determine and monitor the prevalence of cerebral palsy in South Australia
- gather information about affected children that may provide clues to the causes of cerebral palsy
- document the severity and range of disabilities experienced by children with cerebral palsy
- use the information collected to plan facilities for affected children
- act as a source of information about cerebral palsy, for both families and the community
- improve community and professional awareness of cerebral palsy, including its causes and outcomes
- provide a resource for research into cerebral palsy
- contribute to mortality and morbidity studies of cerebral palsy.

Tasmanian Cerebral Palsy Register

ST GILES AND CEREBRAL PALSY ALLIANCE RESEARCH INSTITUTE,
A WHOLLY OWNED SUBSIDIARY OF THE CEREBRAL PALSY ALLIANCE

Target population:

The Register only collects information on cerebral palsy. The main focus is on young children, but accepts registrations from all Tasmanians with cerebral palsy.

Peter Flett or Robyn Sheppard

St Giles

PO Box 45,

New Town,

Tasmania 7008 Australia

society@stgiles.org.au

(03) 6238 1888

Or alternatively Cerebral Palsy Alliance Research Institute at: cpregister@cerebralpalsy.org.au

Purpose:

To monitor how many people are living in Tasmania with cerebral palsy, in which areas they live and whether there are any changing trends in the incidence or severity of CP in the State. The register also aims to facilitate research into the causes, prevention and treatment of CP.

Victorian Cerebral Palsy Register

MURDOCH CHILDRENS RESEARCH INSTITUTE / ROYAL CHILDREN'S HOSPITAL, MELBOURNE

Target population:

Individuals with cerebral palsy born since 1970.

Sue Reid

Murdoch Childrens Research Institute

Royal Children's Hospital

Flemington Road

Parkville

Victoria 3052 Australia

sue.reid@mcri.edu.au

(03) 9345 4807

Purpose:

- To determine the frequency and describe the characteristics of CP in Victoria
- To enable research into aetiology
- To select cohorts for intervention and other studies.

Western Australian Register of Developmental Anomalies - Cerebral Palsy

Target population:

All individuals from birth-year 1956 who have CP acquired before age 5 years and were born or currently live in WA.

Linda Watson

Telethon Institute for Child Health Research

PO Box 855

West Perth

WA 6872 Australia

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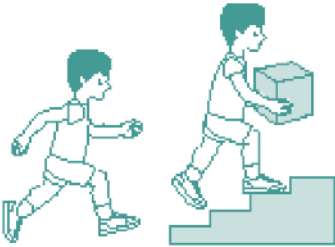
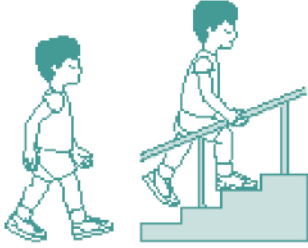
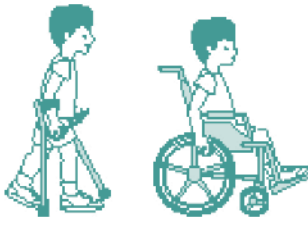
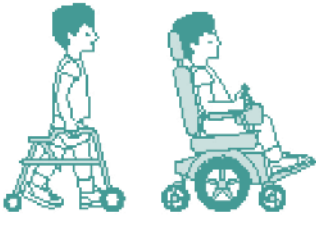
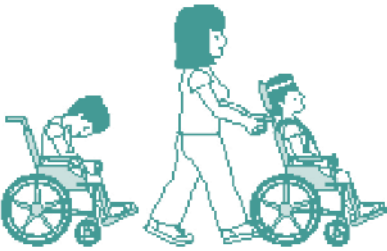
Web: http://www.kemh.health.wa.gov.au/services/register_developmental_anomalies/

Purpose:

- To monitor trends in the CPs and identify areas of concern for future investigation
- To conduct population based epidemiological studies of the various CP subgroups, particularly to elucidate causes
- To evaluate changes in antenatal, obstetric and neonatal care in relation to CP as an index of neurological outcome
- To identify CP as an outcome in other study populations
- To aid in the planning of services for individuals with CP by providing distribution of CP in WA by age, severity, geographical area, etc to service organisations
- To contribute WA CP data to the Australian Cerebral Palsy Register.

APPENDIX B

Gross Motor Function System – descriptors and illustrations

	<p>GMFCS Level I</p> <p>Children walk indoors and outdoors and climb stairs without limitation. Children perform gross motor skills including running and jumping, but speed, balance and co-ordination are impaired.</p>
	<p>GMFCS Level II</p> <p>Children walk indoors and outdoors and climb stairs holding onto a railing but experience limitations walking on uneven surfaces and inclines and walking in crowds or confined spaces.</p>
	<p>GMFCS Level III</p> <p>Children walk indoors or outdoors on a level surface with an assistive mobility device. Children may climb stairs holding onto a railing. Children may propel a wheelchair manually or are transported when traveling for long distances or outdoors on uneven terrain.</p>
	<p>GMFCS Level IV</p> <p>Children may continue to walk for short distances on a walker or rely more on wheeled mobility at home and school and in the community.</p>
	<p>GMFCS Level V</p> <p>Physical impairment restricts voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Children have no means of independent mobility and are transported.</p>

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APPENDIX C

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Recommended citation:
Report of the Australian Cerebral Palsy Register, Birth Years 1993-2006, February 2013.

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