Australian Cerebral Palsy Register

Report 2009

Birth Years 1993-2003

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ACKNOWLEDGEMENTS

The ACPR group would like to sincerely thank all the families and health professionals who are involved in this Australia wide effort. The ACPR Group is committed to collect the most accurate and complete data possible in order to monitor cerebral palsy in Australia, identify causal pathways, and evaluate prevention and management strategies for the benefit of those with cerebral palsy and their families.

The ACPR Group would like to both acknowledge and thank Shelly Healey at The Spastic Centre for the design of this report. The ACPR Group would also like to thank Hayley Smithers-Sheedy, Research Officer for the ACPR, particularly for her integral role in the development and completion of this report.

The Australian Cerebral Palsy Register (ACPR) is hosted at the Cerebral Palsy Institute in Sydney. The Cerebral Palsy Institute is grateful to the Cerebral Palsy Foundation for its ongoing financial support of the ACPR. Sincere thanks also to the team at Hostworks for their on-going support of the ACPR and for their professionalism and efficiency.

The staff at the Cerebral Palsy 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 Register - Cerebral Palsy Institute, The Spastic Centre of NSW, The Australian National University
- Northern Territory Cerebral Palsy Register - Department of Health and Families
- Queensland Cerebral Palsy Register - Cerebral Palsy League of Queensland
- The South Australian Cerebral Palsy Register - Children, Youth and Women's Health Service
- Tasmanian Cerebral Palsy Register - Menzies Research Institute
- Victorian Cerebral Palsy Register - Murdoch Children's Research Institute, Royal Children's Hospital, Melbourne
- Western Australia Cerebral Palsy Register - Telethon Institute for Child Health Research.


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FOREWORD

Karin B. Nelson, MD is a child neurologist, scientist emeritus at the US National Institute of Neurological Disorders and Stroke and works part-time at the Children's Hospital National Medical Centre, Washington DC.

If you look up 'cerebral palsy register' on *PubMed*, as I did, you will discover that the first entry is the 1981 paper of Fiona Stanley, from Western Australia. In the following year came a paper from Fiona and Eve Blair, and thereafter others from Western Australia, the UK, and then - as the value of cerebral palsy registers became more generally understood - from a variety of other countries and regions. Now we see the happy development of the Australian CP Register, incorporating information from the whole of Australia.

What are cerebral palsy registers good for? Descriptive epidemiology, with information on prevalence and changes in prevalence over time, and in different regions (metropolitan and rural WA, e.g.), and for studies of natural history. Analytic epidemiology, with studies of etiology and, in the future, studies of interventions, preventive and therapeutic.

The original registry founded by Fiona, joined by Eve and others, has already contributed hugely to our knowledge that the old assumptions needed revising, that acute asphyxial incidents were more common in the births of babies with later-recognized CP than in other infants, but did not account for most CP. Papers from the WA registry, and subsequently registries in other states, notably from Victoria and South Australia, have used analytic epidemiology in combination with other methodologies, to teach the world more about what really does cause CP. The first controlled and population-based study of Neonatal Encephalopathy, a hugely important pathway to CP that remains - still, to this day - amazingly under-researched, came from WA; relating encephalopathy in the term neonate to long-term outcome depended on the use of registry data.

With the coming-together of data on CP from all the states of Australia, the All-Australia CP Registry will be a magnificent resource for the future, largely eliminating the need for expensive and potentially biased clinical follow-up studies. With the advent of computerized medical record systems - on maternal, pregnancy and birth histories, placental findings, genetic data, etc. - the registry will make it possible to connect the dots in ways they have not been connected before, enabling new research that can tackle questions that no single institution or plausible collaboration has yet touched. Congratulations to those who have worked so hard to accomplish this.

Professor Karin Nelson

AUSTRALIAN CEREBRAL PALSY REGISTER REPORT PLAIN ENGLISH FACT SHEET

Fact Sheet for Consumers and Media

What is cerebral palsy?

Cerebral palsy is a life-long physical disability due to damage of the developing brain. Movement and posture are affected. It shows itself first in early childhood.

For 94% of people with cerebral palsy, the brain injury occurs before 1 month of age.

The most common presentation of cerebral palsy is known as spastic hemiplegia, where one half of the body has difficulty with voluntary movement. Approximately 40% have hemiplegia.

How common is cerebral palsy?

Cerebral palsy is the most common physical disability in childhood affecting approximately one in 500 children. A child is born with cerebral palsy every 15 hours.

In 13 out of every 14 cases in Australia the brain injury leading to cerebral palsy occurs either in the uterus or before 1 month of age. Another 1 in 14 children acquire cerebral palsy after 1 month of age.

What are the causes?

At present the cause is not well understood for most children who acquire cerebral palsy before 1 month of age.

Stroke is the most common cause in children who acquire cerebral palsy after 1 month of age. Stroke can occur spontaneously or arise from surgical or heart complications.

What are the effects?

Spasticity is the term used to describe the very tight muscles that are a problem in 86% of children with cerebral palsy. Spasticity makes movement more difficult and sometimes painful.

Over 28% of Australian children with cerebral palsy cannot walk. Another, 11% require a walking frame or sticks to walk.

Children with cerebral palsy are likely to also have other impairments in addition to their motor disability. 60% have a speech impairment; 45% have an intellectual impairment; 31% have epilepsy; 37% have a vision impairment and 12% have a hearing impairment.

The rate of birth defects (congenital abnormalities) is at least 5 times higher in children with cerebral palsy than the general population. Between 20% and 40% have a birth defect.

Who is at greater risk?

1. **Males**
   Males are at greater risk of having cerebral palsy.

2. **Premature babies**
   Prematurity is associated with higher rates of cerebral palsy.

   42% of children with cerebral palsy are born prematurely, compared to 8% of the Australian population.

3. **Small babies**
   Low birth weight is associated with higher rates of cerebral palsy. This may be a result of prematurity or slow intrauterine growth.

   43% of children with cerebral palsy had low birth weight, compared to just over 6% of the Australian population.

4. **Twins, triplets and higher multiple births.**
   Multiple births are associated with higher rates of cerebral palsy.

   11% of children with cerebral palsy were from a multiple birth, whereas the rates of multiple births are only 1.7% in the Australian population.

The Australian Cerebral Palsy Register

The Australian Cerebral Palsy Register is a major tool that will help identify causes of cerebral palsy and look at the effectiveness of current and future interventions aimed at treatment or prevention.

EXECUTIVE SUMMARY

The Australian Cerebral Palsy Register (ACPR) is a research database 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 is de-identified and is securely uploaded from each state and territory cerebral palsy register in Australia. This is the inaugural report of combined state dataset. The data pertains to birth years 1993-2003. For this report, data was uploaded to the ACPR database in August 2009. Any cases notified to state/territory registers after this date are 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 have registered all (or very nearly all) eligible persons. All these registers report cerebral palsy rates exceeding 1.5/1000 live births per year. The population registers' data have been combined in this report for the first time. For data integrity, if there were fields from these registers in which more than 20% was missing/unknown, the data was not combined. Cerebral palsy registries have been established more recently in the Australian Capital Territory, New South Wales, Northern Territory, Queensland and Tasmania. Pleasingly the numbers of persons ascertained is increasing rapidly in these states and territories, but they cannot yet be considered to represent population registers. Data from these states and territories are not combined with the population registers and are presented throughout the report in tables only.

From the data of the 3 established population registers there were a total of 2391 individuals with cerebral palsy; an Australian cerebral palsy prevalence of 2.0/1000 live births (95%CI 1.9-2.1). For 5.3% their brain injury was acquired during a recognised event occurring more than 28 days after birth. For the remaining 94.7%, 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 1.9/1000 (95%CI 1.8-2.0).

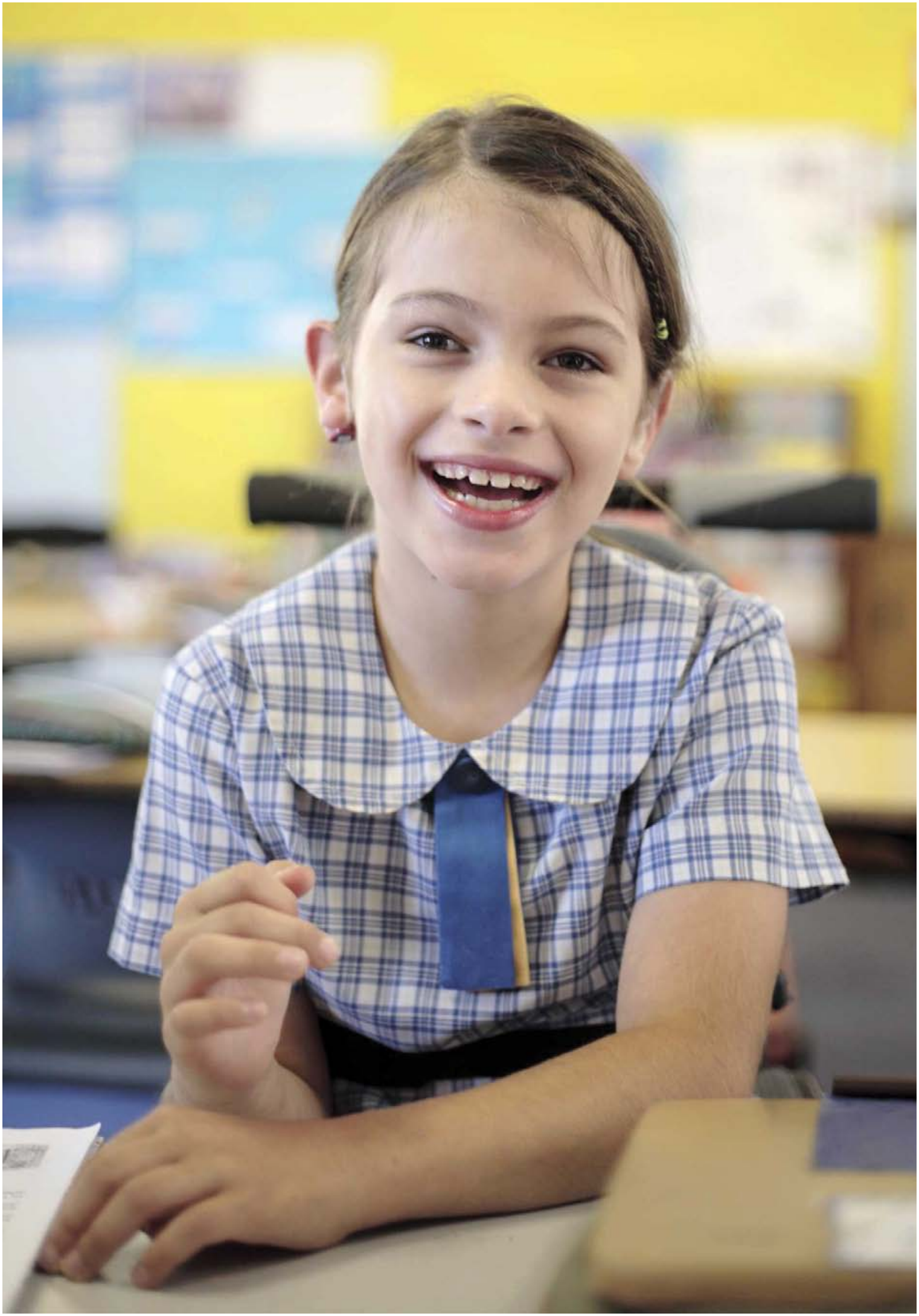
The following key findings pertain to this latter cohort of pre and perinatally acquired cerebral palsy born 1993-2003 inclusive, excluding the 5.3% post neonatally acquired.

The cause of brain injury is not well understood for the great majority (97.7%) of these infants but up to 37% also had an identified birth defect suggesting some anomaly in prenatal development. There was an excess of males (56.4%) compared to the Australian birth population in which 51.5% were male. Aboriginal and or Torres Strait Islander mothers were over represented with 3.4% compared to 0.9% in the three combined states.

Compared with the Australian birth population in which 7.9% were born before 37 weeks gestation (premature), 41.5% of this cerebral palsy cohort were born premature. In the general population, the rate of premature birth is slowly rising over time and survival following birth after very short gestations is also increasing in developed countries. This is a concern because the risk of cerebral palsy increases exponentially with increasing prematurity. Similarly, compared with the Australian birth population in which 6.3% are born with weights below 2500g (low birth weight), 42.5% of infants with cerebral palsy were born with a low birth weight. Prematurity and low birth weight are associated with multiple births; 11% of this cerebral palsy cohort were part of a multiple birth compared with 1.7% of the Australian birth population.

Spasticity was the predominant motor type of cerebral palsy (85%) with unilateral spasticity (hemiplegia/monoplegia) making up 38% and bilateral spasticity (diplegia, triplegia and quadriplegia) predominant with 62%. Associated impairments occurred frequently in children with cerebral palsy: 30% had epilepsy; 45% an intellectual impairment; 60% a speech impairment; 37% a vision impairment and 12% had a hearing impairment with 50% having more than one associated impairment.

Based on 127 individuals, the prevalence of post-neonatally acquired cerebral palsy was estimated to be 1.08/10,000 live births. The predominant post-neonatal cause was a cerebro-vascular accident (35%) being either spontaneous, associated with surgery or with complications of cardiac defects.



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ABOUT CEREBRAL PALSY

Cerebral palsy is the most common physical disability in childhood. Cerebral palsy occurs at a rate of 2-2.5 per 1000 live births in developed countries [1, 2].

There has been considerable debate in recent times as to how to best define cerebral palsy [3]. Both internationally and in Australia, cerebral palsy registers have drawn on a range of references and perspectives when considering the best definition [4]. The ACPR has adopted the approach used by the Surveillance of cerebral palsy in Europe [5], allowing the use of any definition that includes the following five key elements, common to the definitions published by Bax [6], Rosenbaum [3] and Mutch [7].

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 [5].

For the majority of individuals with cerebral palsy the cause is not well understood. Cerebral palsy is associated with numerous perinatal factors e.g., rubella or cytomegalovirus infections, preterm birth, intrauterine growth restriction, perinatal asphyxia and multiple pregnancy and with post-neonatal factors such as head trauma or cerebral infections [8].

Motor disability ranges from minimal to profound, and the risks of epilepsy and intellectual, speech, visual, hearing, and gastro-intestinal impairments increase as motor impairment increases, which can greatly contribute to overall disability [9].

Care is costly, particularly for those with multiple associated disabilities and the expenditure for cerebral palsy care has been estimated at an average of $43,431 per person p.a. of which approximately 37% is borne by the individual and/or their family [9]. When a value for lost well-being is included, this cost estimate increases to $115,000 per person p.a. [9]. It is estimated that 34,000 people are living with cerebral palsy in Australia with an estimated expenditure of $1.47 billion per year [9]. It is expected that this number of people with cerebral palsy will increase to 47,601 by 2050 as the population increases and life expectancies of those with cerebral palsy increase.

There is no specific pre-birth test for cerebral palsy and there is no cure, therefore it is a life long disability.

WHAT IS THE AUSTRALIAN CEREBRAL PALSY REGISTER?

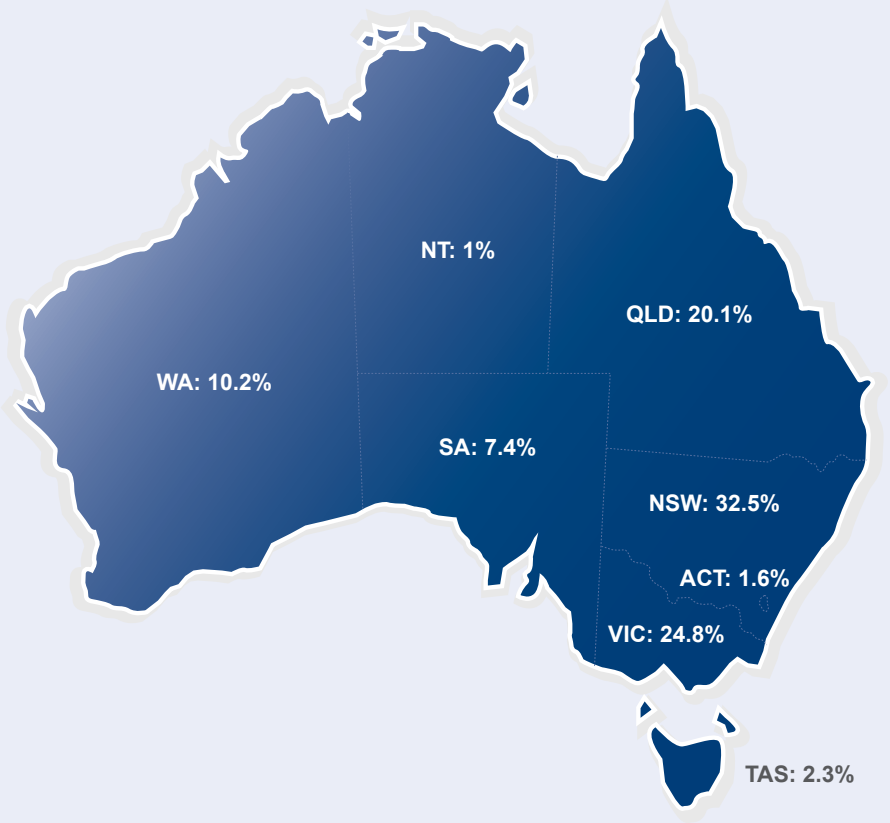
The ACPR is an electronic database of data uploaded from the cerebral palsy registers in each state and territory of Australia, from which client identifiers have been removed and replaced by a unique code in order to ensure privacy of data.

The ACPR exists as a result of collaborative partnerships between all 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 (ACT) and New South Wales Cerebral Palsy Register (NSW)
  - Cerebral Palsy Institute, The Spastic Centre of NSW
- Northern Territory (NT) Cerebral Palsy Register
  - Department of Health and Families
- Queensland (QLD) Cerebral Palsy Register
  - Cerebral Palsy League of Queensland
- The South Australian (SA) Cerebral Palsy Register
  - Children, Youth and Women's Health Service
- Tasmanian (TAS) Cerebral Palsy Register
  - Menzies Research Institute
- Victorian (VIC) Cerebral Palsy Register
  - Murdoch Children's Research Institute, Royal Children's Hospital, Melbourne
- Western Australia (WA) Cerebral Palsy Register
  - Telethon Institute for Child Health Research

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 million people [10] with the bulk of the population living along the eastern seaboard. For a more detailed description of each of the state and territory cerebral palsy registers, including contact details, please see Appendix A.

Figure 1: Population proportions for the states and territories of Australia [10]



AIMS OF THE ACPR

The overarching vision for the ACPR, is that the register should exist 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 of the ACPR is to be a source of data that will support research relating to:

a) monitoring of cerebral palsy

b) identifying interventions that effectively improve quality of life

c) identifying causal pathways to enable prevention

d) evaluation of future prevention strategies

The ACPR Research and Policy Group includes a representative from each state and territory cerebral palsy 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@tscnsw.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 a National Health and Medical Research Council (NH&MRC) approved HREC.

The Cerebral Palsy Institute (CPI) is the custodian organisation for the ACPR. Both the CPI and the ACPR are funded by the Cerebral Palsy Foundation which is a wholly owned company of The Spastic Centre of NSW.

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 the:

- Development of the *Report of the international survey of cerebral palsy registers and surveillance systems, 2009* which is available at: **http://www.cpinstitute.com.au publications/index.html**

- Hosting of the World Register Congress as part of the International Cerebral Palsy Conference in Sydney 2009.

  This congress provided researchers and clinicians from around the world with a dedicated period of time at this event to present the latest available cerebral palsy surveillance data, share information and discuss register and surveillance issues. A summary document of the discussion forum has been prepared and can be requested by contacting: **cpregister@tscnsw.org.au**

- 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 **http://intersect.cpinstitute.org.au**

The work of cerebral palsy 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 cerebral palsy registers in Australia.

METHODS

Cohort
The cohort selected for this report was the birth years 1993-2003. In order to ensure that duplicate cases were not included in the dataset, each state and territory group contributed 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 duplicate records. Cases born outside of Australia but currently living in Australia were not included in this report, but it is intended that these cases will be included in future reports.

Inclusion/exclusion criteria
In order to be included in the dataset, a case must fulfil the criteria contained in the five definitional elements [5] as outlined above. Where a case has met these criteria and there is evidence of a chromosomal anomaly, genetic syndrome or metabolic disease the principles provided by Badawi et al [11] were used by contributing registers to guide decisions regarding whether the case should be included.

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, included or excluded at any time.

Denominator data
Data on live births for the years 1993-2003 (the denominator) was obtained from a variety of sources including the Australian Institute of Health and Welfare - Consultative Council on Obstetric and Paediatric Mortality and Morbidity Annual Reports, the Australian Bureau of Statistics and Annual Reports of the Pregnancy Outcome Unit (SA).

Eligibility criteria for combining datasets
There is considerable variation across each state and territory in relation to the level of ascertainment of cases achieved for each year in the 1993-2003 period. This is due to a number of factors, including significant variation in the length of time registers have been in existence (see description of cerebral palsy registers in the Appendix A), and also reflects differences in registrant consent requirements across the states and territories.

Where a prevalence of at least 1.5/1000 live births across the cohort period has been established (see Figure 3, page 18) by a state or territory, data have been combined where appropriate and reported in comparison charts. State or territory cohort data that do not meet this criterion have been included in data tables only. Where more than 20% of data are missing or unknown, these data have been included in data tables only.

Results
The results of this report have been divided into three sections. Part 1 refers to all cerebral palsy cases, Part 2 refers to cerebral palsy 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 cerebral palsy cases where a known post-neonatal (occurring after 28 days of life and before 2 years of age) cause has been identified [12]. The results have been presented in this format as the majority of pre/perinatal causes of cerebral palsy are unknown, whereas the likely cause has been identified in post-neonatally acquired cases.

The ACPR began collecting Manual Ability Classification System (MACS) data in recent years, and as such data is limited and has not been included in this report. It is expected that data pertaining to this classification scale will be provided in future ACPR reports.

RESULTS

Part 1:

All cerebral palsy cases

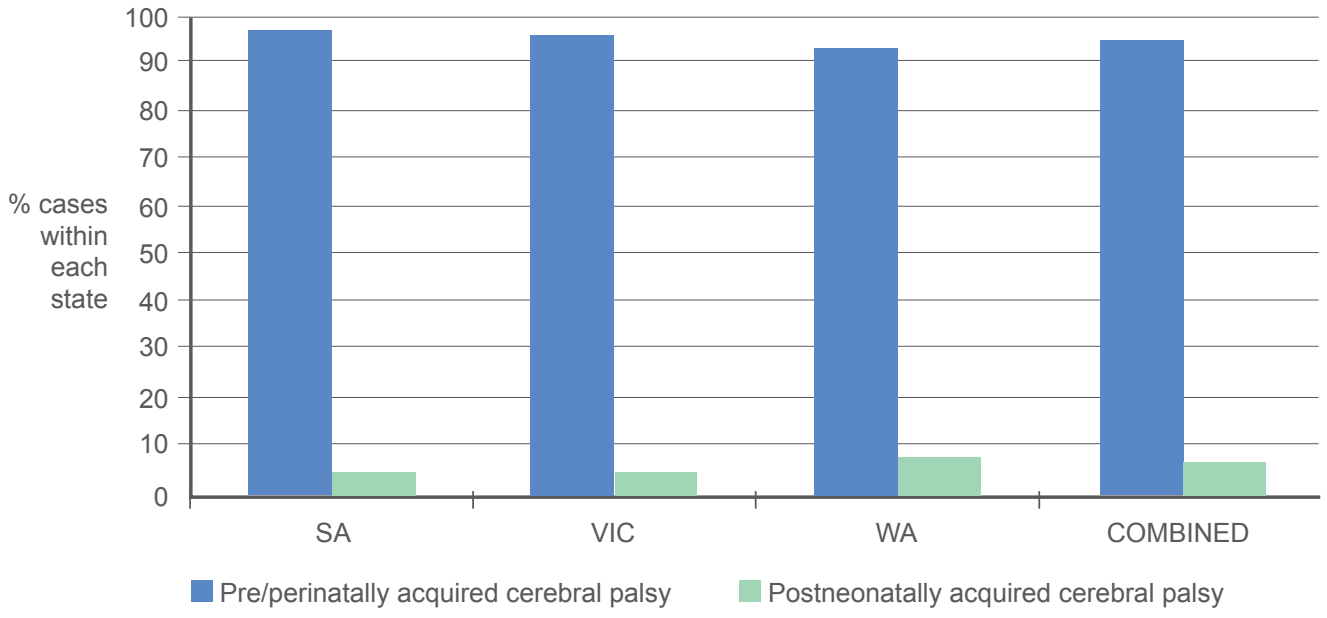
Table 1. **Pre/perinatally and post-neonatally acquired cerebral palsy (CP) by state/territory of birth (1993-2003).**

	Live births (1993-2003) n	Pre/perinatally acquired CP n (%)	Post-neonatally acquired CP n (%)	TOTAL n	Prevalence (per 1000 live births) All CP cases
ACT	46372	42 (85.7)	7 (14.3)	49	-
NSW	955471	570 (91.6)	52 (8.4)	622	-
NT	40383	* (100.0)	* (0.0)	2	-
QLD	518563	137 (93.8)	9 (6.2)	146	-
SA	**204204**	**367 (96.6)**	**13 (3.4)**	**380**	**1.9 (95% CI 1.7-2.1)**
TAS	67747	38 (97.4)	* (2.6)	39	-
VIC	**689802**	**1195 (95.4)**	**58(4.6)**	**1253**	**1.8 (95% CI 1.7-1.9)**
WA	**276318**	**702 (92.6)**	**56 (7.4)**	**758**	**2.7 (95% CI 2.5-2.9)**
TOTAL		***3053***	***196***	***3249***	
COMBINED SA, VIC, WA	**1,170,324**	**2264 (94.7)**	**127 (5.3)**	**2391**	**2.0 (95% CI 1.9, 2.1)**

* < 5 cases

For this first report of the ACPR, data pertaining to 3249 individuals with cerebral palsy are reported. In this cohort the total prevalence for cerebral palsy, is 2.0 per 1000 live births (95% CI 1.9-2.1)

Figure 2. **Percentages of pre/perinatally and post-neonatally acquired cerebral palsy by state of birth (1993-2003).**



In this cohort the combined data indicate that the brain injury responsible for cerebral palsy primarily arises during the pre/perinatal period (94.7%). For a small group (5.3%) the brain injury occurred post-neonatally.

RESULTS

Part 2:

Prenatally or perinatally acquired cerebral palsy cases

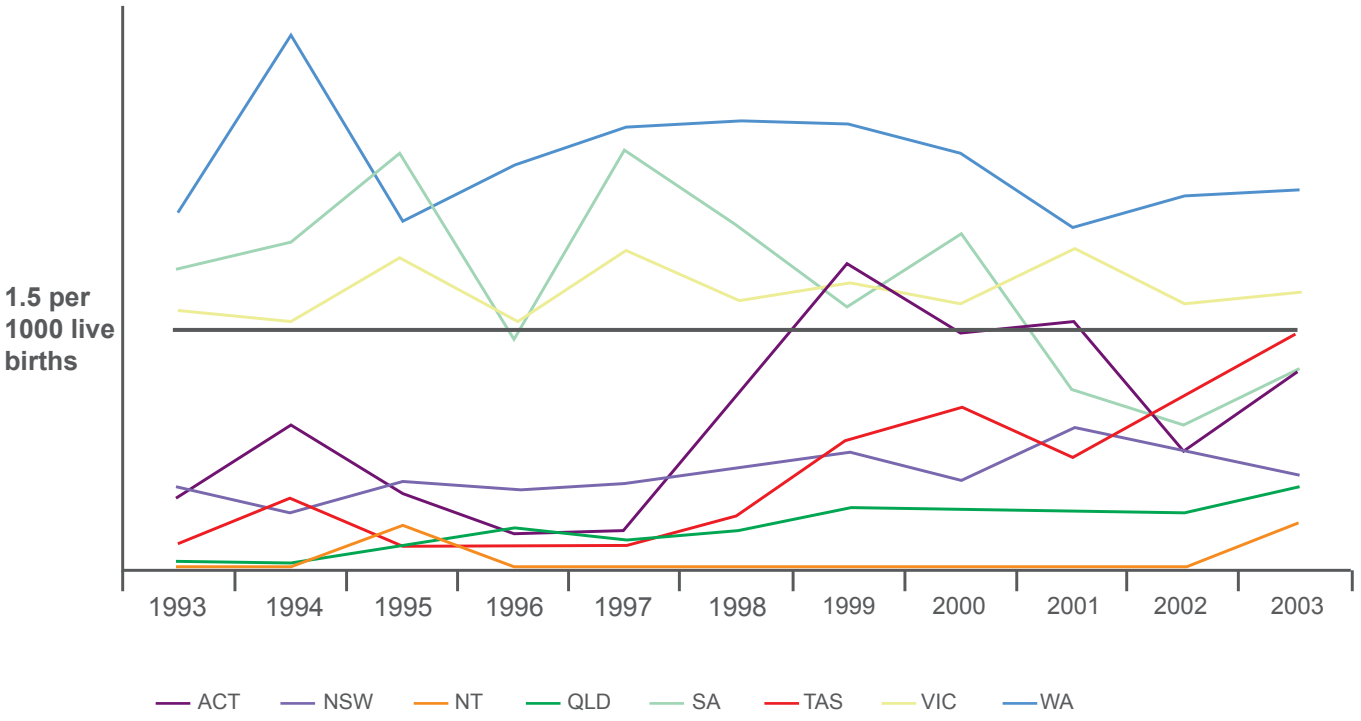
Prenatally or perinatally acquired cerebral palsy

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 the first 28 completed days after birth).

Eligibility criteria for combining datasets

As stated previously, where a prevalence of at least 1.5/1000 live births across the cohort period has been established (see Figure 3 below) by a state or territory, data have been combined where appropriate and reported in comparison charts. State or territory cohort data that do not meet this criterion have been included in data tables only. Where more than 20% of data are missing or unknown, these data have been included in data tables only.

Figure 3. Current ascertainment of cases by each birth state/territory (1993-2003), excluding cases with known post-neonatal causes, and the birth prevalence of cerebral palsy 1.5/1000 live births required for combining datasets.



Cohort of cases of cerebral palsy (1993-2003)

Table 2. Prevalence of cerebral palsy (CP) by year and state or territory (1993-2003), excluding cases with known post-neonatal causes.

	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	1993-2003
ACT												
Live Births (LB)	4414	4461	4415	4396	4208	3982	4253	4065	3938	4112	4128	46372
CP cases	*	*	*	*	*	*	8	6	6	*	5	42
CP cases/1000 LB	-	-	-	-	-	-	**1.88**	**1.48**	**1.52**	-	**1.21**	-
NSW												
Live Births (LB)	89354	87977	87849	86595	87156	85499	86784	86752	84578	86583	86344	955471
CP cases	45	31	48	44	46	55	64	48	75	63	51	570
CP cases/1000 LB	**0.50**	**0.35**	**0.55**	**0.51**	**0.53**	**0.64**	**0.74**	**0.55**	**0.89**	**0.73**	**0.59**	-
NT												
Live Births (LB)	3603	3626	3766	3562	3588	3641	3576	3685	3822	3724	3790	40383
CP cases	*	*	*	*	*	*	*	*	*	*	*	2
CP cases/1000 LB	**0.00**	**0.00**	-	**0.00**	**0.00**	**0.00**	**0.00**	**0.00**	**0.00**	**0.00**	-	-
QLD												
Live Births (LB)	46778	46578	46484	47769	46965	47046	45874	47278	47678	47771	48342	518563
CP cases	*	*	8	11	9	11	17	18	17	17	25	137
CP cases/1000 LB	**0.04**	**0.04**	**0.17**	**0.23**	**0.19**	**0.23**	**0.37**	**0.38**	**0.36**	**0.36**	**0.52**	-
SA												
Live Births (LB)	19846	19673	19472	18979	18535	18613	18404	17765	17584	17623	17710	204204
CP cases	37	40	50	27	48	40	30	37	20	16	22	367
CP cases/1000 LB	**1.86**	**2.03**	**2.57**	**1.42**	**2.59**	**2.15**	**1.63**	**2.14**	**1.14**	**0.91**	**1.24**	**1.8 (95%CI 1.6-2.0)**
TAS												
Live Births (LB)	6795	6787	6748	6278	6249	6115	6082	5914	5666	5641	5472	67747
CP cases	*	*	*	*	*	*	5	6	*	6	8	38
CP cases/1000 LB	-	-	-	-	-	-	**0.82**	**1.01**	**0.71**	**1.06**	**1.46**	-
VIC												
Live Births (LB)	64284	64376	63214	62484	61867	61686	62442	62144	61690	62678	62937	689802
CP cases	104	100	122	96	122	103	111	103	122	104	108	1195
CP cases/1000 LB	**1.62**	**1.55**	**1.93**	**1.54**	**1.97**	**1.67**	**1.78**	**1.66**	**1.98**	**1.66**	**1.72**	**1.7 (95%CI 1.6-1.8)**
WA												
Live Births (LB)	25187	25260	25285	25419	25151	25466	25614	25057	24773	24607	24499	276318
CP cases	56	84	54	64	69	71	71	65	53	57	58	702
CP cases/1000 LB	**2.22**	**3.33**	**2.18**	**2.52**	**2.74**	**2.79**	**2.77**	**2.59**	**2.14**	**2.32**	**2.37**	**2.5 (95%CI 2.3-2.7)**
TOTAL PRENATALLY/PERINATALLY ACQUIRED CEREBRAL PALSY CASES FOR AUSTRALIAN CEREBRAL PALSY REGISTER (1993-2003)												***3053***

Birth prevalence of cerebral palsy (excluding cases with known post-neonatal causes)

Figure 4. **Birth prevalence of cerebral palsy per 1000 live births (LB) by state and year of birth (1993-2003), excluding cases with known post-neonatal causes.**

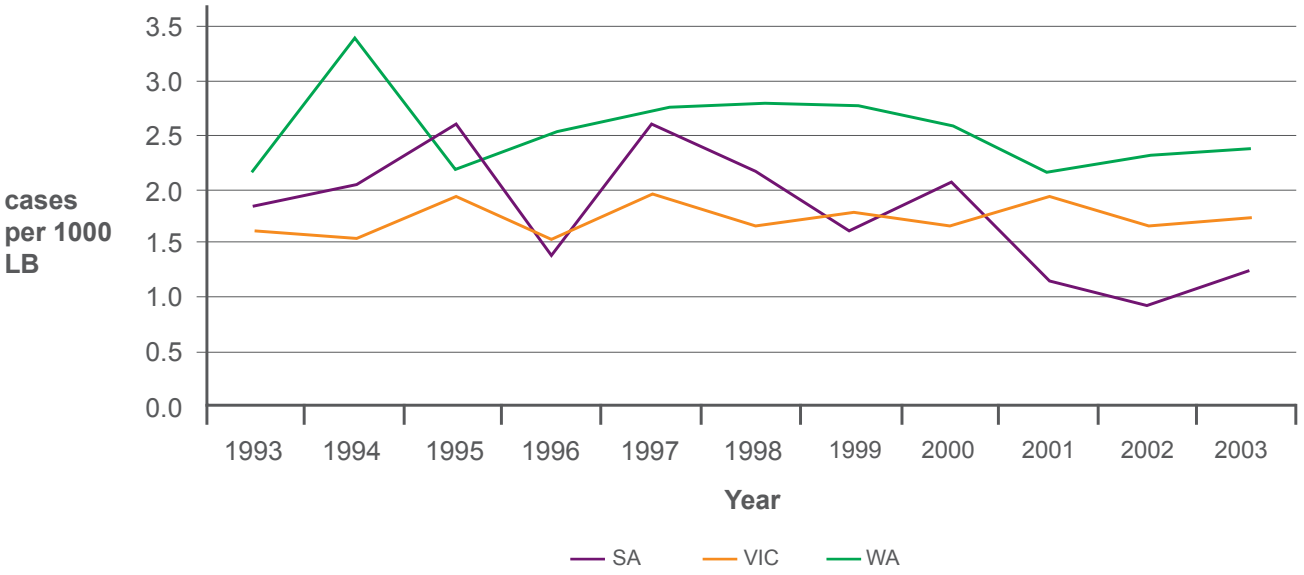


Figure 5. **Total prevalence (95% confidence intervals) of cerebral palsy per 1000 live births by state (1993-2003), excluding cases with known post-neonatal causes.**

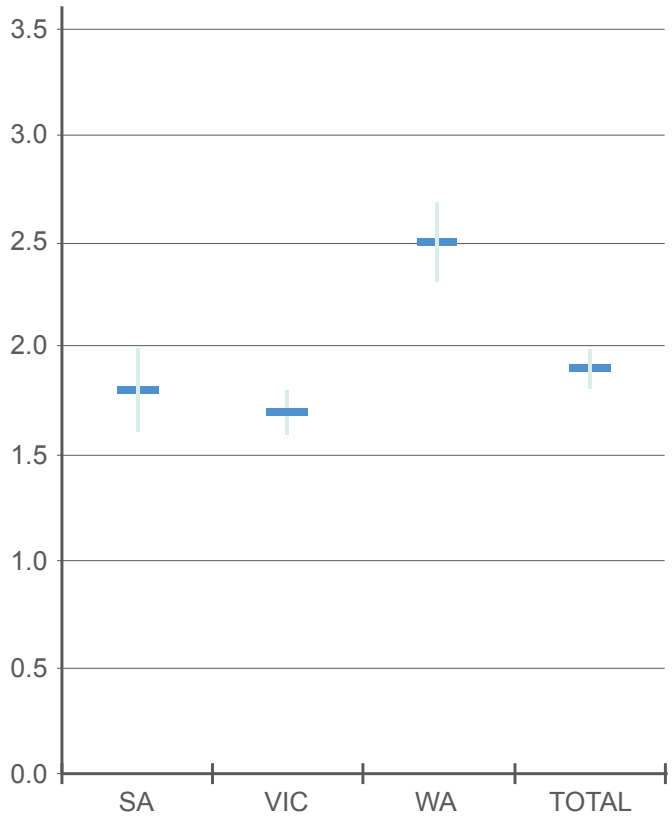


Table 3. **Total prevalence of cerebral palsy (CP) per 1000 live births by state (1993 - 2003), excluding cases with known post-neonatal causes.**

	CP CASES	LIVE BIRTHS	PREVALENCE
SA	367	204204	1.8 (95%CI 1.6-2.0)
VIC	1195	689802	1.7 (95%CI 1.6-1.8)
WA	702	276318	2.5 (95% CI 2.3-2.7)
COMBINED TOTAL	**2265**	**1170324**	**1.9 (95% CI 1.8-2.0)**

In this cohort the total birth prevalence for cerebral palsy, excluding cases where a post-neonatal cause has been identified, is 1.9 per 1000 live births (95% CI 1.8-2.0).

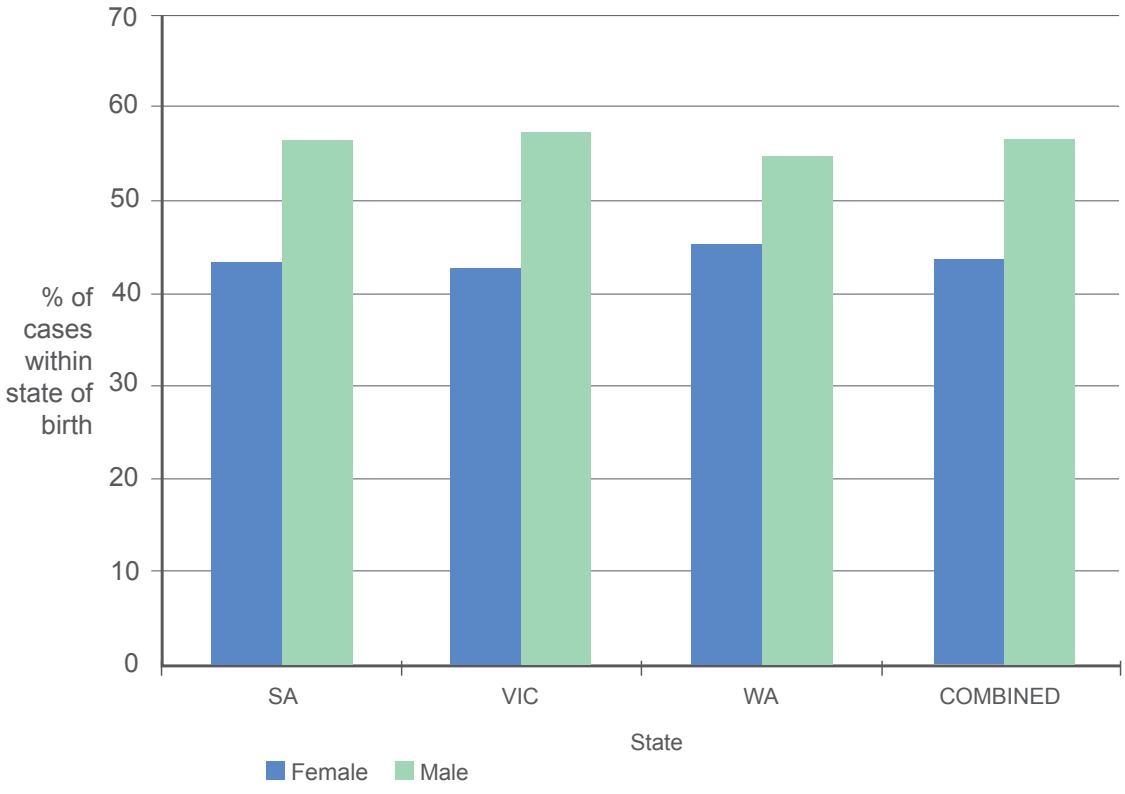
Sex

Table 4. **Number and percentage of cerebral palsy cases by sex and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.**

	Female n (%)	Male n (%)	TOTAL n
ACT	12 (28.6)	30 (71.4)	42
NSW	223(39.0)	347(61.0)	570
NT		* (100.0)	*
QLD	60 (43.8)	77 (56.2)	137
SA	**159 (43.3)**	**208 (56.7)**	**367**
TAS	10 (26.3)	28 (73.7)	38
VIC	**510 (42.7)**	**685 (57.3)**	**1195**
WA	**318 (45.2)**	**384 (54.8)**	**702**
TOTAL	***1291***	***1761***	***3053***
COMBINED SA, VIC, WA	**987 (43.6)**	**1277 (56.4)**	**2264**

* < 5 cases

Figure 6. **Percentages of cerebral palsy cases by sex and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.**



In this cohort the combined data demonstrate that males are at a higher risk of developing cerebral palsy. 56.4% of the cohort were male compared to the Australian population where 51.5% of all births were male [13]

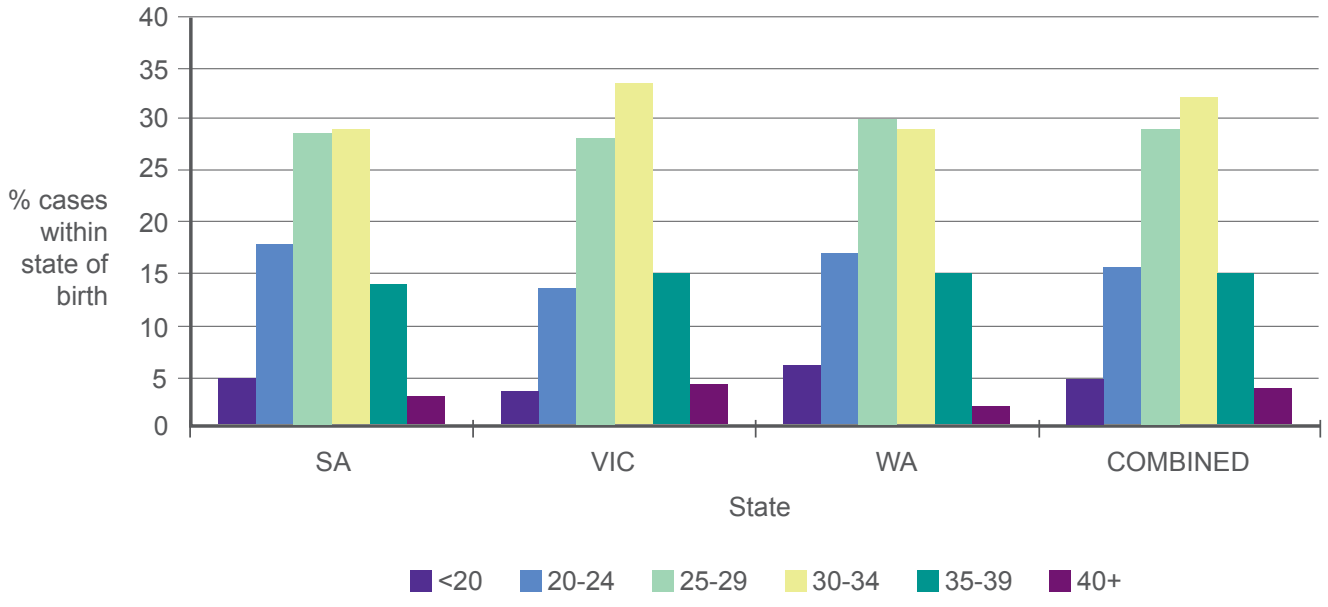
Maternal age at time of delivery.

Table 5. Number and percentage of cerebral palsy cases by maternal age group in years at delivery and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.

	<20 n (%)^	20-24 n (%)^	25-29 n (%)^	30-34 n (%)^	35-39 n (%)^	40+ n (%)^	TOTAL n	Unknown n (%)
ACT	* (7.3)	* (7.3)	6 (14.6)	22 (53.7)	5 (12.2)	* (4.9)	42	* (2.4)
NSW	22 (4.2)	79 (15.1)	134 (25.6)	167 (31.9)	93 (17.7)	29 (5.5)	570	46 (8.1)
NT	*	* (50.0)	*	* (50.0)	*	*	2	0 (0.0)
QLD	8 (6.1)	12 (9.2)	48 (36.6)	39 (29.8)	21(16.0)	* (2.3)	137	6
SA	**18 (5.0)**	**66 (18.4)**	**105 (29.3)**	**106 (29.5)**	**53 (14.8)**	**11 (3.0)**	**367**	**8 (2.2)**
TAS	* (2.6)	8 (21.0)	9 (23.7)	13 (34.2)	* (10.6)	* (7.9)	38	
VIC	**43 (3.7)**	**162 (13.9)**	**328 (28.1)**	**403 (34.5)**	**177 (15.2)**	**54 (4.6)**	**1195**	**28 (2.3)**
WA	**37 (6.1)**	**103 (16.9)**	**186 (30.4)**	**177 (29.1)**	**92(15.1)**	**15 (2.4)**	**702**	**92 (13.1)**
TOTAL	***132***	***434***	***816***	***928***	***445***	***117***	***3053***	***181***
COMBINED SA, VIC, WA	**98 (4.5)**	**331 (15.5)**	**619 (29.0)**	**686 (32.1)**	**322 (15.1)**	**80 (3.8)**	**2264**	**128 (5.6)**

* < 5 cases
(%)^ calculated by n/total n minus unknown n; provided to allow state/territory comparisons

Figure 7. Percentage of cerebral palsy cases by maternal age group in years at delivery and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.



The combined distribution of maternal age at delivery in this cohort is comparable to that of the Australian population [13]

Table 6. **Number and percentage of cerebral palsy cases, by mother's country of birth and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.**

	Oceania and Antartica n (%)^	North and West Europe n (%)^	Southern and Eastern Europe n (%)^	North Africa and Middle East n (%)^	South East Asia n (%)^	North East Asia n (%)^	Southern and Central Asia n (%)^	Americas n (%)^	Subsaharan Africa n (%)^	TOTAL n	Unknown n (%)^
ACT	36 (87.9)	* (4.9)	* (2.4)	0 (0.0)	* (2.4)	* (2.4)	0 (0.0)	0 (0.0)	0 (0.0)	42	* (2.4)
NSW	446 (82.5)	32 (5.9)	6 (1.1)	19 (3.5)	16 (3.0)	6 (1.1)	* (0.7)	* (0.7)	8 (1.5)	570	29 (5.1)
NT	* (100.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	2	0 (0.0)
QLD	119 (88.9)	7 (5.2)	0 (0.0)	0 (0.0)	* (0.7)	* (0.7)	* (1.5)	* (3.0)	0 (0.0)	137	* (2.2)
SA	**322 (95.5)**	*** (0.9)**	*** (0.3)**	*** (0.9)**	*** (1.2)**	**0 (0.0)**	*** (0.3)**	**0 (0.0)**	*** (0.9)**	**367**	**30 (8.2)**
TAS	36 (94.8)	* (2.6)	0 (0.0)	0(0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	* (2.6)	38	(0.0)
VIC	**956 (80.8)**	**64 (5.4)**	**43 (3.6)**	**41 (3.5)**	**31 (2.6)**	**15 (1.3)**	**15 (1.3)**	**5 (0.4)**	**13 (1.1)**	**1195**	**12 (1.0)**
WA	**517 (80.0)**	**79 (12.2)**	**7 (1.1)**	**6 (0.9)**	**10 (1.5)**	*** (0.5)**	**6 (0.9)**	**6 (0.9)**	**12 (1.9)**	**702**	**56 (8.0)**
TOTAL	*2433*	*188*	*58*	*69*	*63*	*26*	*28*	*19*	*37*	*3053*	*132*
COMBINED SA, VIC, WA	**1795 (83.0)**	**146 (6.7)**	**51 (2.3)**	**50 (2.3)**	**45 (2.1)**	**18 (0.8)**	**22 (1.0)**	**11 (0.5)**	**28 (1.3)**	**2264**	**98 (4.3)**

* < 5 cases
(%)^ calculated by n/total n minus unknown n; provided to allow state/territory comparisons

Indigenous status of mother

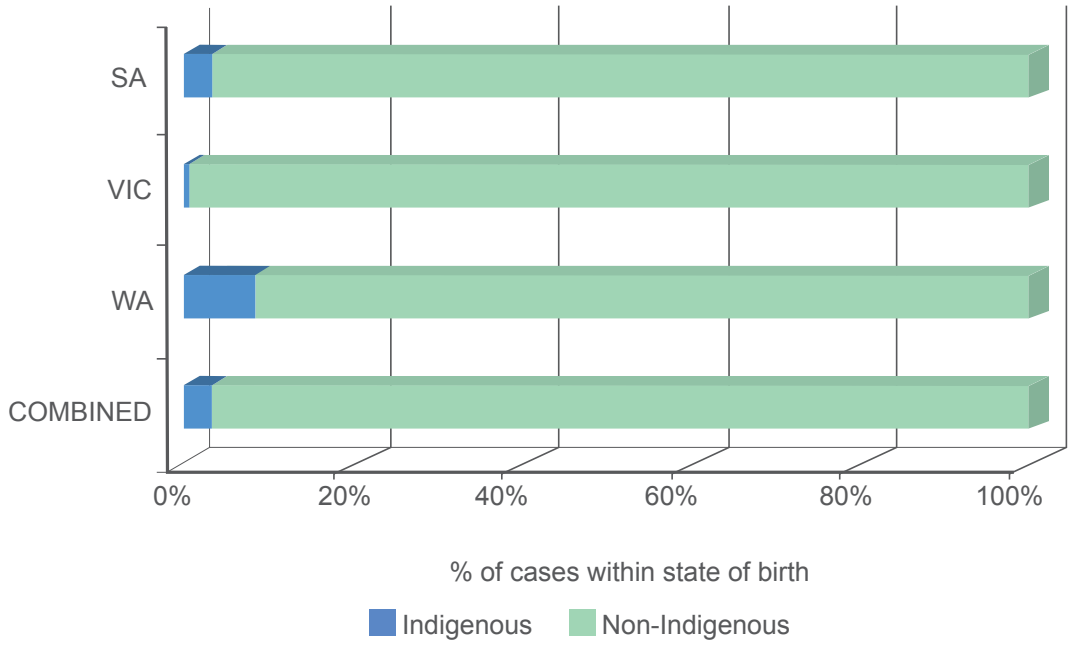
Table 7. Number and percentage of cerebral palsy cases by Indigenous status of mother and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.

	Aboriginal n (%)^	Aboriginal and Torres Strait Islander n (%)^	Torres Strait Islander n (%)^	Non-indigenous n (%)^	TOTAL n (%)	Unknown n (%)
ACT	* (9.7)	0 (0.0)	0 (0.0)	28 (90.3)	42	11 (26.2)
NSW	26 (6.1)	0 (0.0)	0 (0.0)	398 (93.9)	570	146 (25.6)
NT	0 (0.0)	0 (0.0)	0 (0.0)	* (100.0)	2	0 (0.00)
QLD	* (2.8)	* (0.9)	*(0.9)	103 (95.4)	137	29 (21.2)
SA	**11 (3.0)**	**0 (0.0)**	**0 (0.0)**	**350 (97.0)**	**367**	**6 (1.6)**
TAS	* (5.6)	0 (0.0)	0 (0.0)	34 (94.4)	38	* (5.3)
VIC	**7 (0.6)**	**0 (0.0)**	**0 (0.0)**	**1173 (99.4)**	**1195**	**15 (1.3)**
WA	**56 (8.3)**	**0 (0.0)**	**0 (0.0)**	**616 (91.7)**	**702**	**30 (4.3)**
TOTAL	***108***	*****	*****	***2704***	***3053***	***239***
COMBINED SA, VIC, WA	**74 (3.4)**	**0 (0.0)**	**0 (0.0)**	**2139 (96.6)**	**2264**	**51 (2.2)**

*< 5 cases

(%)^ calculated by n/total n minus unknown n; provided to allow state/territory comparisons

Figure 8. Percentage of cerebral palsy cases by Indigenous status of mother and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.



The combined data indicate that Aboriginal and or Torres Strait Islander mothers are over represented in this cohort of cerebral palsy cases. They comprised 3.4% of the cohort compared to 0.9% of the total population in these states [13].

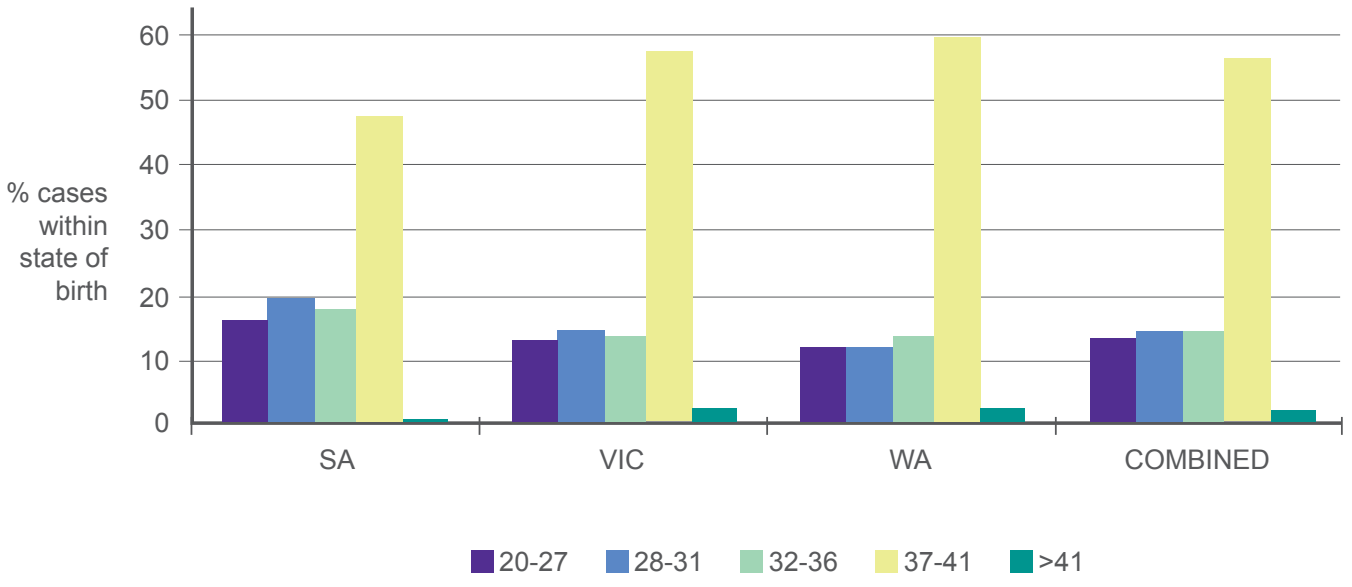
Gestational age at delivery

Table 8. Number and percentage of cerebral palsy cases by gestational age in weeks at delivery and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.

	20-27 n (%)^	28-31 n (%)^	32-36 n (%)^	37-41 n(%)^	>41 n (%)^	TOTAL n	Unknown n (%)
ACT	* (4.8)	11 (26.2)	6 (14.3)	22 (52.3)	* (2.4)	42	0 (0.0)
NSW	85 (15.2)	65 (11.6)	92 (16.4)	289 (51.5)	30 (5.3)	570	9 (1.6)
NT	0 (0.0)	0 (0.0)	0 (0.0)	* (100.0)	0 (0.0)	2	0 (0.0)
QLD	16 (11.9)	29 (21.6)	29 (21.6)	58 (43.4)	* (1.5)	137	3 (2.2)
SA	**57 (15.8)**	**69 (19.1)**	**63 (17.4)**	**170 (47.1)**	*** (0.6)**	**367**	**6 (1.6)**
TAS	6 (15.8)	6 (15.8)	* (10.5)	21 (55.3)	* (2.6)	38	0 (0.0)
VIC	**152 (12.8)**	**167 (14.0)**	**163 (13.7)**	**685 (57.4)**	**25 (2.1)**	**1195**	*** (0.3)**
WA	**84 (12.1)**	**82 (11.8)**	**96 (13.8)**	**413 (59.7)**	**18 (2.6)**	**702**	**9 (1.3)**
TOTAL	***402***	***429***	***453***	***1660***	***79***	***3053***	***30***
COMBINED SA, VIC, WA	**293 (13.1)**	**318 (14.1)**	**322 (14.3)**	**1268 (56.5)**	**45 (2.0)**	**2264**	**18(0.8)**

* < 5 cases
(%)^ calculated by n/total n minus unknown n; provided to allow state/territory comparisons

Figure 9. Percentage of cerebral palsy cases by gestational age in weeks at delivery and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.



In this cohort the combined data indicate that 41.5% of cerebral palsy births were premature (< 37weeks gestation). This is in contrast to the Australian population where 7.9% of all births were premature [12].

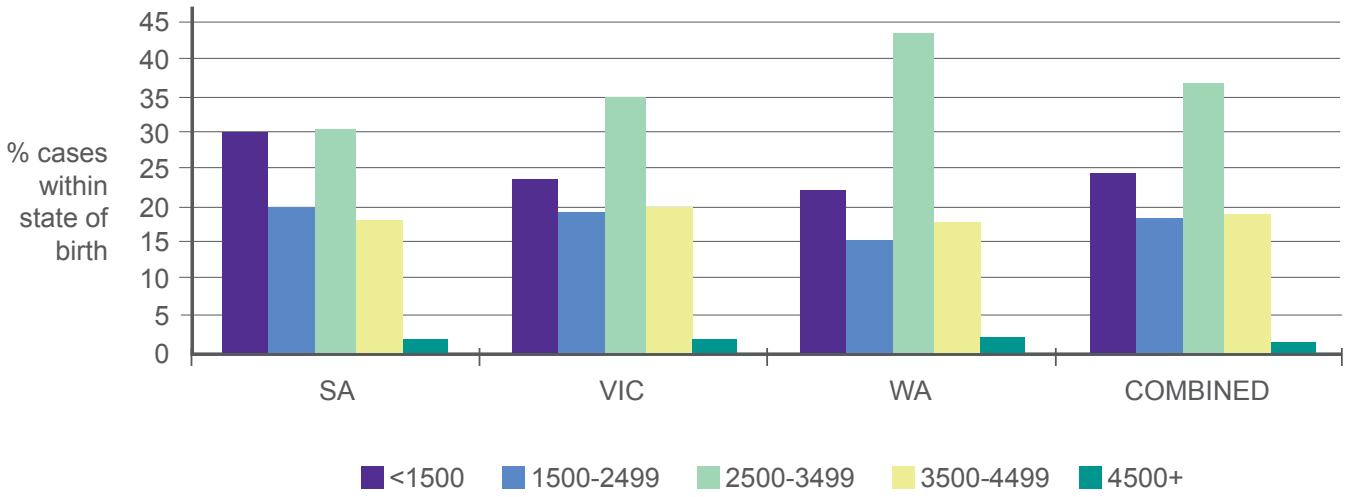
Birth weight

Table 9. Number and percentage of cerebral palsy cases by birth weight in grams and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.

	<1500 n (%)^	1500-2499 n (%)^	2500-3499 n (%)^	3500-4499 n (%)^	4500+ n (%)^	TOTAL N	Unknown n (%)
ACT	12 (29.3)	5 (12.2)	14 (34.1)	8 (19.5)	* (4.9)	42	* (2.4)
NSW	143 (26.0)	106 (19.3)	188 (34.3)	106 (19.3)	6 (1.1)	570	21 (3.7)
NT	0 (0.0)	0 (0.0)	* (100.0)	0 (0.0)	0 (0.0)	2	0 (0.0)
QLD	39 (29.1)	32 (23.9)	47 (35.1)	15 (11.2)	* (0.7)	137	* (2.2)
SA	**108 (30.1)**	**71 (19.8)**	**109 (30.4)**	**64 (17.8)**	**7 (1.9)**	**367**	**8 (2.2)**
TAS	8 (23.5)	6 (17.6)	13 (38.3)	7 (20.6)	0 (0.0)	38	* (10.5)
VIC	**282 (23.8)**	**229 (19.3)**	**413 (35.0)**	**237 (20.0)**	**23 (1.9)**	**1195**	**11 (0.9)**
WA	**152 (22.1)**	**105 (15.3)**	**299 (43.5)**	**123 (17.9)**	**8 (1.2)**	**702**	**15 (2.1)**
TOTAL	***744***	***554***	***1085***	***560***	***47***	***3053***	***63***
COMBINED SA, VIC, WA	**542 (24.3)**	**405 (18.2)**	**821(36.8)**	**424 (19.0)**	**38 (1.7)**	**2264**	**34(1.5)**

* < 5 cases
(%)^ calculated by n/total n minus unknown n; provided to allow state/territory comparisons

Figure 10. Percentage of cerebral palsy cases by birth weight in grams and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.



In this cohort the combined data show that 42.5% of infants with cerebral palsy were born at a low birth weight (< 2500 grams). In comparison, low birthweight in the Australian population was present in 6.3% of live births [13].

Plurality

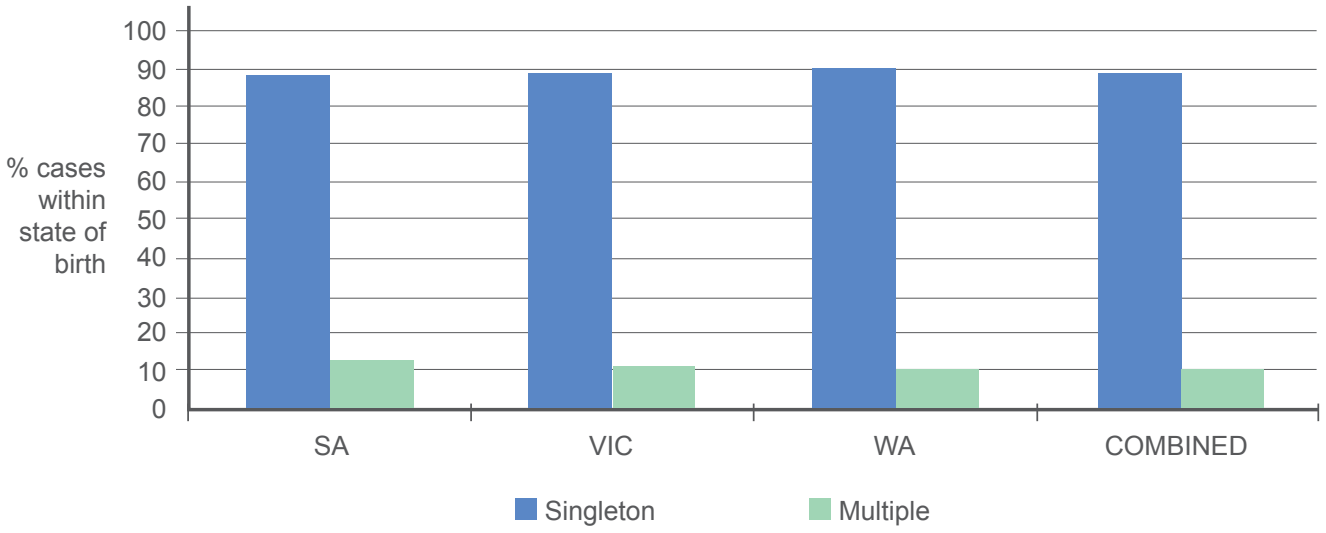
Table 10. Number and percentage of cerebral palsy cases by birth plurality and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.

Birth Plurality	Singletons n (%)^	Multiples n (%)^	TOTAL n	Unknown n (%)
ACT	31 (83.8)	6 (16.2)	42	5 (11.9)
NSW	476(86.8)	72 (13.2)	570	22 (3.9)
NT	* (100.0)	0 (0.0)	2	0 (0.0)
QLD	112 (84.8)	20 (15.2)	137	5 (3.6)
SA	**321 (87.9)**	**44 (12.1)**	**367**	*** (0.5)**
TAS	32 (84.2)	6 (15.8)	38	0 (0.0)
VIC	**1045 (88.8)**	**132 (11.2)**	**1195**	**18 (1.5)**
WA	**620 (89.6)**	**72 (10.4)**	**702**	**10 (1.4)**
TOTAL	***2639***	***352***	***3053***	***62***
COMBINED SA, VIC, WA	**1986 (88.9)**	**248 (11.1)**	**2264**	**30 (1.3)**

* < 5 cases

(%)^ calculated by n/total n minus unknown n; provided to allow state/territory comparisons

Figure 11. Percentage of cerebral palsy cases by birth plurality and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.



In this cohort the combined data indicate that 11.1% of those with cerebral palsy were from a multiple birth. In the Australian population multiple births account for 1.7% of all births [12].

Assisted conception

Table 11: Number and percentage of cerebral palsy cases by type of assisted conception and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.

	Unassisted Conception n (%)^	Fertility drugs only n (%)^	Artificial Insemination n (%)^	IVF n (%)^	ICSI n (%)^	GIFT n (%)^	Assisted conception NOS n (%)^	TOTAL n	Unknown n (%)
ACT	39 (97.5)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	* (2.5)	42	* (4.8)
NSW	499 (90.4)	13 (2.4)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	40 (7.2)	570	18 (3.2)
NT	* (100.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	2	0 (0.0)
QLD	121 (90.3)	6 (4.5)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	7 (5.2)	137	* (2.2)
SA	239 (89.8)	* (1.5)	* (1.1)	14 (5.3)	0 (0.0)	* (0.8)	* (1.5)	367	101 (27.5)
TAS	36 (94.8)	* (2.6)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	* (2.6)	38	0 (0.0)
VIC	**938 (95.6)**	*** (0.2)**	*** (0.3)**	**26 (2.7)**	**6 (0.6)**	*** (0.4)**	*** (0.2)**	**1195**	**214 (17.9)**
TOTAL	***1874***	***26***	***6***	***40***	***6***	***6***	***55***	***2351***	***338***

Note: WA data not included at this time.

* < 5 cases
(%)^ calculated by n/total n minus unknown n; provided to allow state/territory comparisons

There is presently too much missing and unknown data in this field of the ACPR to allow combining of data; however, data obtained from Victoria suggests that 3.9% of cerebral palsy cases were conceived using assisted reproductive technologies between 1993 and 2003 compared with 0.03% of live births in Australia in 2003 [14].

Prenatal/perinatal causes of cerebral palsy

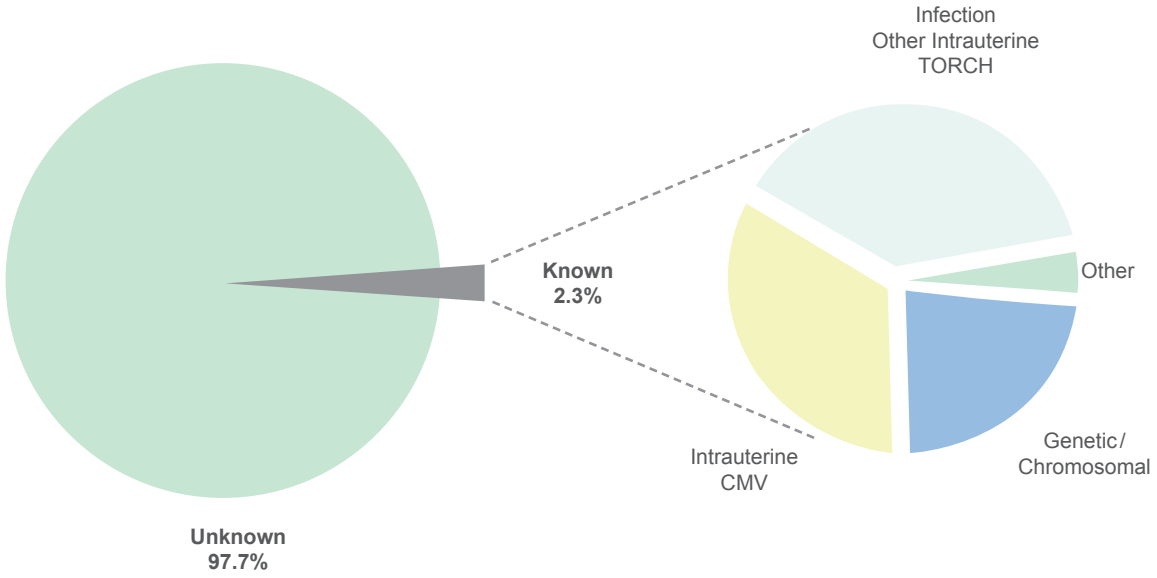
Table 12. Number and percentage of cerebral palsy cases by pre/perinatal cause and state/ territory of birth (1993-2003).

Birth State	Genetic / Chromosomal n (%)	Intrauterine CMV n (%)	Other Intrauterine TORCH Infection n (%)	Other Prenatal Cause Unspecified n (%)	TOTAL n	Unknown N (%)
COMBINED SA, VIC, WA	**13 (0.5)**	**19 (0.8)**	**22 (0.9)**	*** (0.1)**	**2405**	**2348 (97.7)**

Note: ACT, NSW, NT, QLD, TAS data not included at this time.

* <5 cases

Figure 12. Percentage of cerebral palsy cases by pre/perinatal cause, South Australia, Victoria and Western Australia combined (1993-2003).



In this cohort the combined data indicate that for the majority (97.7%) of cases the pre/perinatal causes are not completely understood.

Predominant motor type

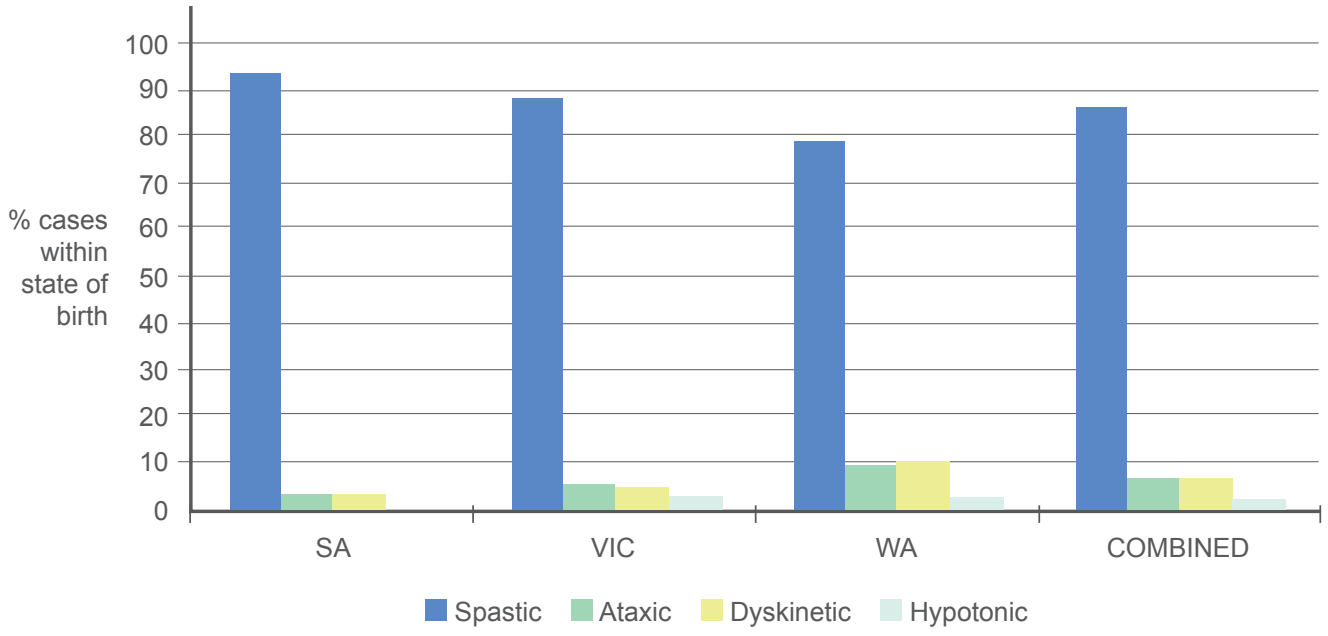
Table 13. Number and percentage of cerebral palsy cases by predominant motor type and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.

	Spastic n (%)^	Ataxic n (%)^	Dyskinetic n (%)^	Hypotonic n (%)^	TOTAL n	Unknown n (%)
ACT	28 (87.4)	* (6.3)	* (6.3)	0 (0.0)	42	10 (23.8)
NSW	452 (85.3)	28 (5.3)	33 (6.2)	17 (3.2)	570	40 (7.0)
NT	* (100.0)	0 (0.0)	0 (0.0)	0 (0.0)	2	0 (0.0)
QLD	91 (92.9)	* (1.0)	* (4.1)	* (2.0)	137	39 (28.5)
SA	**342 (94.0)**	**11 (3.0)**	**11 (3.0)**	**0 (0.0)**	**367**	**3 (0.8)**
TAS	24 (96.0)	* (4.0)	0 (0.0)	0 (0.0)	38	13 (34.2)
VIC	**1035 (87.9)**	**61 (5.2)**	**54 (4.6)**	**27 (2.3)**	**1195**	**18 (1.5)**
WA	**551 (78.5)**	**64 (9.1)**	**71 (10.1)**	**16 (2.3)**	**702**	**0 (0.0)**
TOTAL	***2525***	***168***	***175***	***62***	***3053***	***123***
COMBINED SA, VIC, WA	**1928 (85.9)**	**136 (6.1)**	**136 (6.1)**	**43 (1.9)**	**2264**	**21 (1.6)**

* < 5 cases

(%)^ calculated by n/total n minus unknown n; provided to allow state/territory comparisons

Figure 13. Percentage of cerebral palsy cases by predominant motor type and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.



In this cohort the combined data indicate that spasticity was the most predominant motor type of cerebral palsy (85.9%)

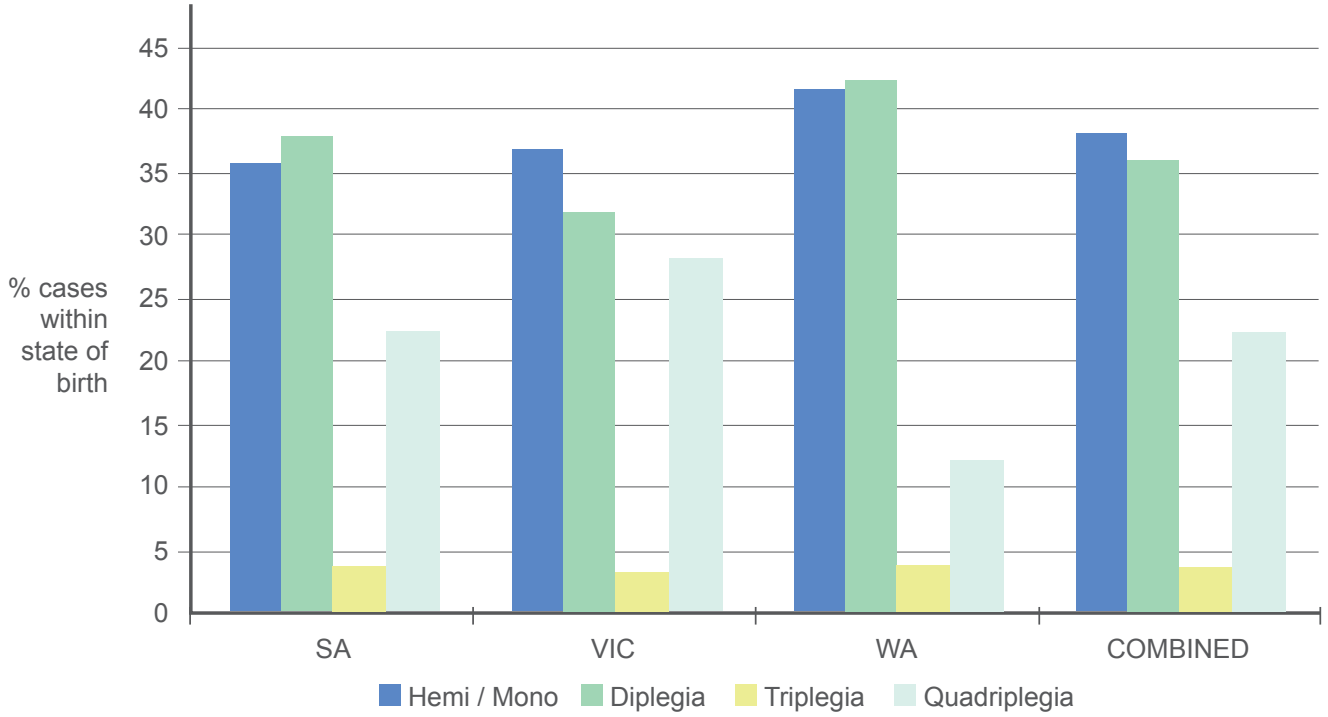
Topographical pattern of spasticity

Table 14. Number and percentage of cerebral palsy cases by topographical pattern of spasticity where spasticity is the predominant motor type and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.

	Monoplegia / Hemiplegia n (%)	Diplegia n (%)	Triplegia n (%)	Quadriplegia n (%)	TOTAL n
ACT	10 (35.7)	6 (21.4)	0 (0.0)	12 (42.9)	28
NSW	184 (40.7)	120 (26.5)	10 (2.2)	138 (30.5)	452
NT	* (50.0)	* (50.0)	0 (0.0)	0 (0.0)	2
QLD	38 (41.7)	32 (35.2)	* (2.2)	19 (20.9)	91
SA	**123 (35.9)**	**129 (37.8)**	**13 (3.8)**	**77 (22.5)**	**342**
TAS	9 (37.5)	6 (25.0)	* (8.3)	7 (29.2)	24
VIC	**381 (36.8)**	**329 (31.8)**	**33 (3.2)**	**292 (28.2)**	**1035**
WA	**229 (41.7)**	**235 (42.6)**	**21 (3.8)**	**66 (12.0)**	**551**
TOTAL	***975***	***858***	***81***	***611***	***2525***
COMBINED SA, VIC, WA	**733 (38.0)**	**693 (36.0)**	**67 (3.5)**	**435 (22.5)**	**1928**

* < 5 cases

Figure 14. Percentage of cerebral palsy cases by topographical pattern of spasticity where spasticity is the predominant motor type and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.



In this cohort the combined data indicate that hemiplegia (including monoplegia) or unilateral spastic cerebral palsy (38%) is the most common topographical pattern of spasticity. However if diplegia, triplegia and quadriplegia are grouped as bilateral spastic cerebral palsy [15], this pattern was predominant (62%) [15].

Gross motor function

Table 15. Number and percentage of cerebral palsy cases by Gross Motor Function Classification System (GMFCS) levels and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.

	I n (%)^	II n (%)^	III n (%)^	IV n (%)^	V n (%)^	TOTAL n	Unknown n(%)
ACT	10 (31.2)	6 (18.8)	5 (15.6)	5 (15.6)	6 (18.8)	42	10 (23.8)
NSW	161 (33.5)	90 (18.8)	62 (12.9)	71 (14.8)	96 (20.0)	570	90 (15.8)
NT	* (50.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	2	* (50.0)
QLD	44 (50.0)	20 (22.7)	10 (11.4)	* (4.5)	10 (11.4)	137	49 (35.8)
SA	142 (49.7)	49 (17.1)	25 (8.7)	31 (10.8)	39 (13.6)	367	81 (22.1)
TAS	* (28.6)	* (14.3)	0 (0.0)	* (42.8)	* (14.3)	38	31 (81.6)
VIC	**355 (31.9)**	**300 (26.9)**	**129 (11.6)**	**158 (14.2)**	**172 (15.4)**	**1195**	**81 (6.8)**
TOTAL	***715***	***466***	***231***	***272***	***324***	***2351***	***343***

Note 1: WA data not included at this time.
Note 2: An example of the Gross Motor Function Classification System descriptors have been provided in Appendix B

*< 5 cases
(%)^ calculated by n/total n minus unknown n; provided to allow state/territory comparisons

In this cohort the data from Victoria indicate that at the age of 5 years the most predominant levels of gross motor function are GMFCS I and II (58.8%). 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

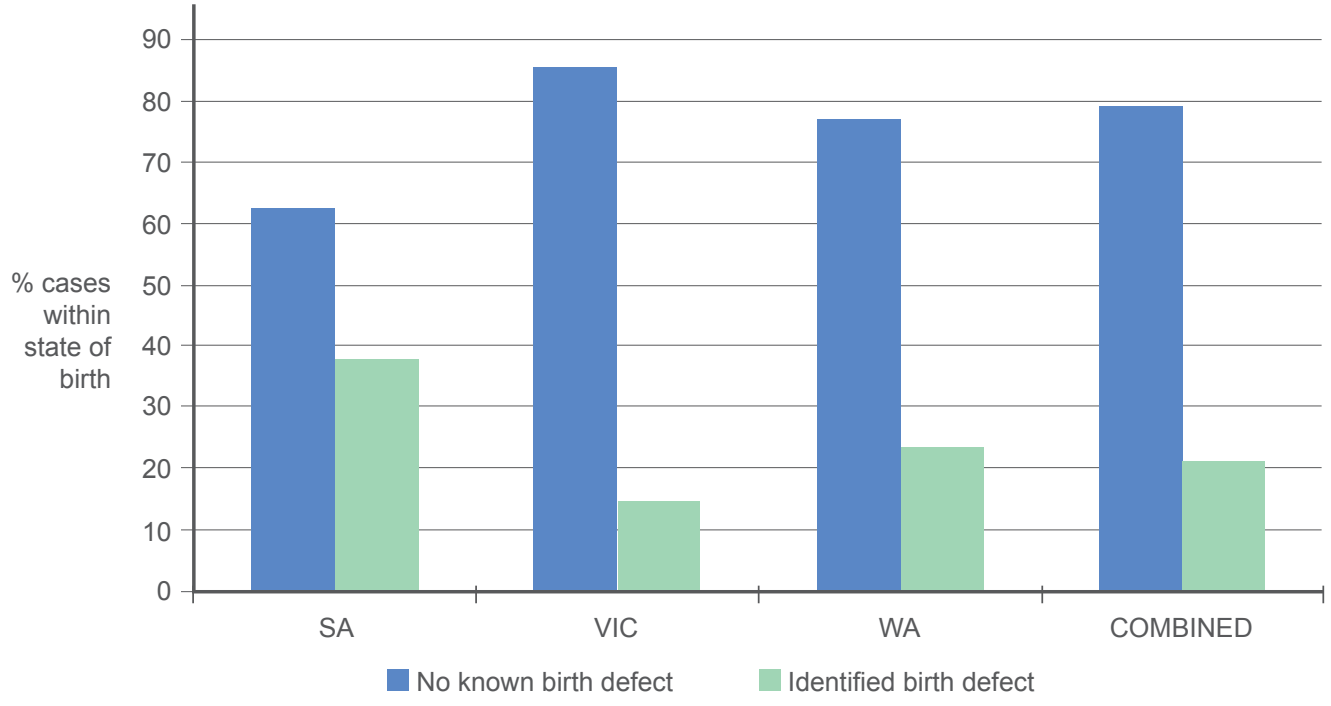
Table 16. Number and percentage of cerebral palsy cases - identified birth defects by state/ territory of birth (1993-2003), excluding cases with known post-neonatal causes.

	No known birth defect n (%)^	Birth defect n (%)^	TOTAL n	Unknown n (%)
ACT	34 (85.0)	6 (15.0)	42	* (4.8)
NSW	435 (82.7)	91 (17.3)	570	44 (7.7)
NT	* (100.0)	0 (0.0)	2	0 (0.0)
QLD	101 (78.9)	27 (21.1)	137	9 (6.6)
SA	**229 (62.4)**	**138 (37.6)#**	**367**	**0 (0.0)**
TAS	29 (93.5)	* (6.5)	38	7 (18.4)
VIC	**1013 (85.3)**	**175 (14.7)**	**1195**	**7 (0.6)**
WA	**524 (76.7)**	**159 (23.3)**	**702**	**19 (2.8)**
TOTAL	***2366***	***598***	***3053***	***89***
COMBINED SA, VIC, WA	**1766 (78.9)**	**472(21.1)**	**2264**	**26(1.5)**

The SA Cerebral Palsy 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.

*< 5 cases
(%)^ calculated by n/total n minus unknown n; provided to allow state/territory comparisons

Figure 15. Percentage of cerebral palsy cases - identified birth defects by state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.



In this cohort, the combined data indicate that 21% of children with cerebral palsy also had an identified birth defect. This figure is likely to be as high as 37%. Compared with the Australian population figure of 4.5-5.6%.

Associated disorders or impairments at 5 years of age

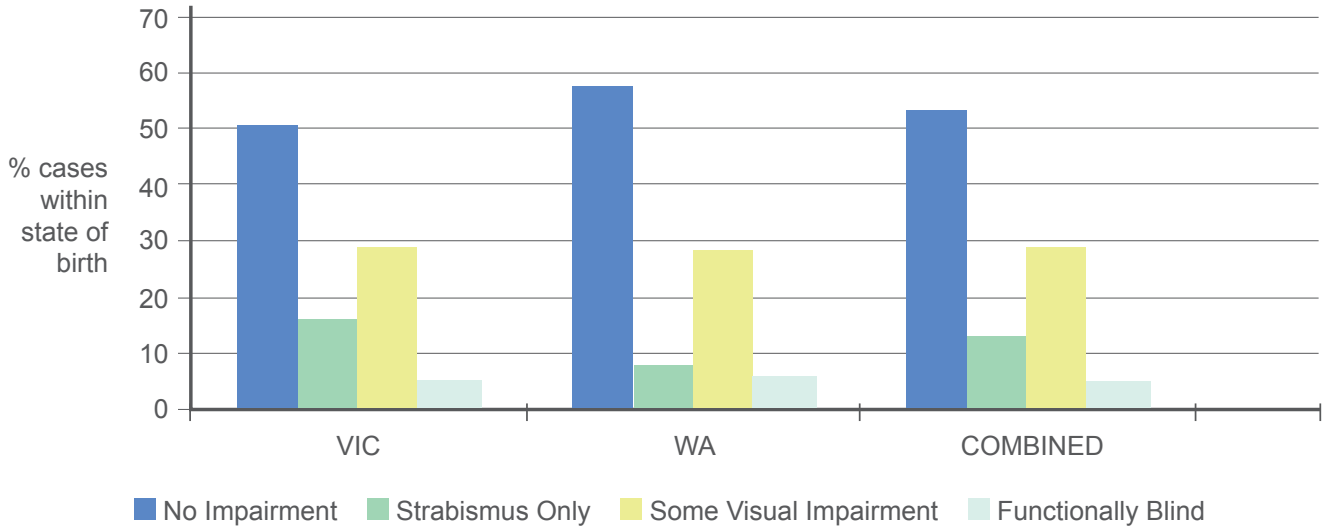
Vision

Table 17. Number and percentage of cerebral palsy cases by vision status and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.

	No impairment n (%)^	Strabismus only n (%)^	Some visual impairment n (%)^	Functionally blind n (%)^	TOTAL n	Unknown n (%)
ACT	22 (56.4)	* (10.3)	11 (28.2)	* (5.1)	42	* (7.1)
NSW	304 (57.4)	50 (9.4)	156 (29.3)	21 (3.9)	570	39 (6.8)
NT	* (100.0)	0 (0.0)	0 (0.0)	0 (0.0)	*	0 (0.0)
QLD	79 (64.2)	20 (16.3)	20 (16.3)	4 (3.2)	137	14 (10.2)
SA	147 (57.7)	12 (4.7)	85 (33.3)	11 (4.3)	367	112 (30.5)
TAS	27(77.2)	* (5.7)	5 (14.3)	* (2.8)	38	* (7.9)
VIC	**564 (50.4)**	**180 (16.1)**	**321 (28.6)**	**55 (4.9)**	**1195**	**75 (6.3)**
WA	**391 (57.5)**	**54 (7.9)**	**193 (28.4)**	**41(6.0)**	**702**	**23 (3.3)**
TOTAL	***1536***	***322***	***791***	***135***	***3053***	***269***
COMBINED VIC, WA	**955 (53.1)**	**234 (13.0)**	**514 (28.6)**	**96 (5.3)**	**1897**	**98 (5.1)**

* < 5 cases
(%)^ calculated by n/total n minus unknown n; provided to allow state/territory comparisons

Figure 16. Percentage of cerebral palsy cases by vision status and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.



Hearing

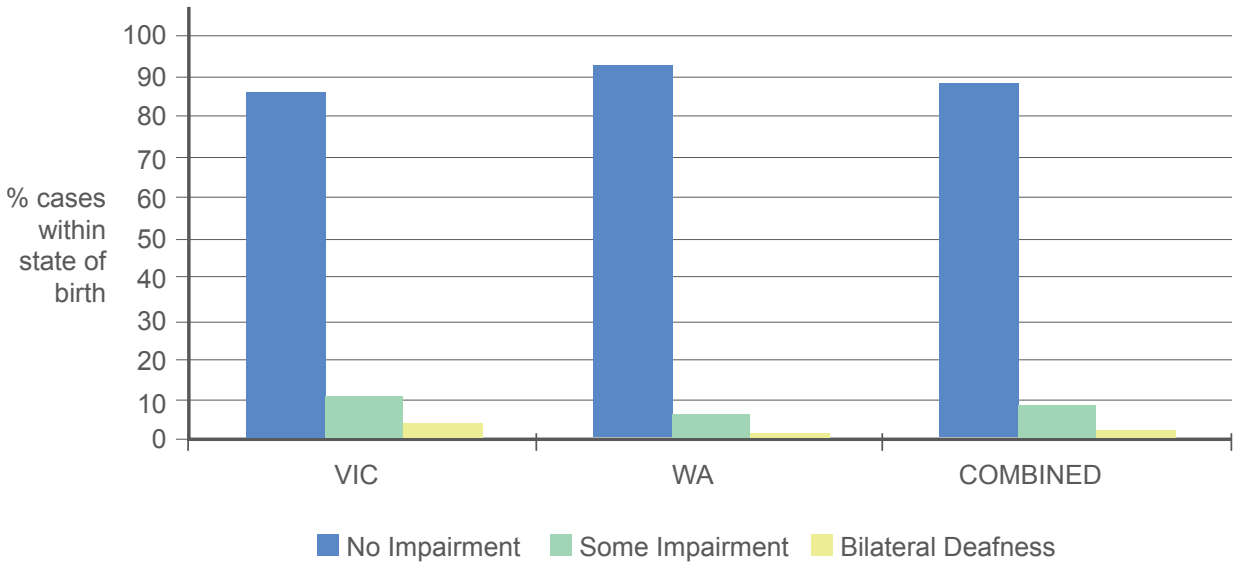
Table 18. Number and percentage of cerebral palsy cases by hearing status and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.

	No impairment n (%)^	Some impairment n (%)^	Bilateral deafness n (%)^	TOTAL n	Unknown n (%)
ACT	37 (92.5)	* (5.0)	* (2.5)	42	* (4.8)
NSW	473 (89.1)	38 (7.0)	21 (3.9)	570	38 (6.3)
NT	* (100.0)	0 (0.0)	0 (0.0)	2	* (0.0)
QLD	114 (89.1)	11 (8.6)	* (2.3)	137	9 (6.6)
SA	226 (86.3)	29 (11.1)	7 (2.7)	367	105 (28.6)
TAS	36 (97.3)	* (2.7)	*0 (0.0)	38	* (2.6)
VIC	**946 (85.7)**	**120 (10.9)**	**38 (3.4)**	**1195**	**91 (7.6)**
WA	**613 (91.9)**	**42 (6.3)**	**12 (1.8)**	**702**	**35 (5.0)**
TOTAL	***2449***	***243***	***82***	***3053***	***279***
COMBINED VIC, WA	**1559 (88.1)**	**162 (9.1)**	**50 (2.8)**	**1897**	**126 (6.6)**

* < 5 cases

(%)^ calculated by n/total n minus unknown n; provided to allow state/territory comparisons

Figure 17. Percentage of cerebral palsy cases by hearing status and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.



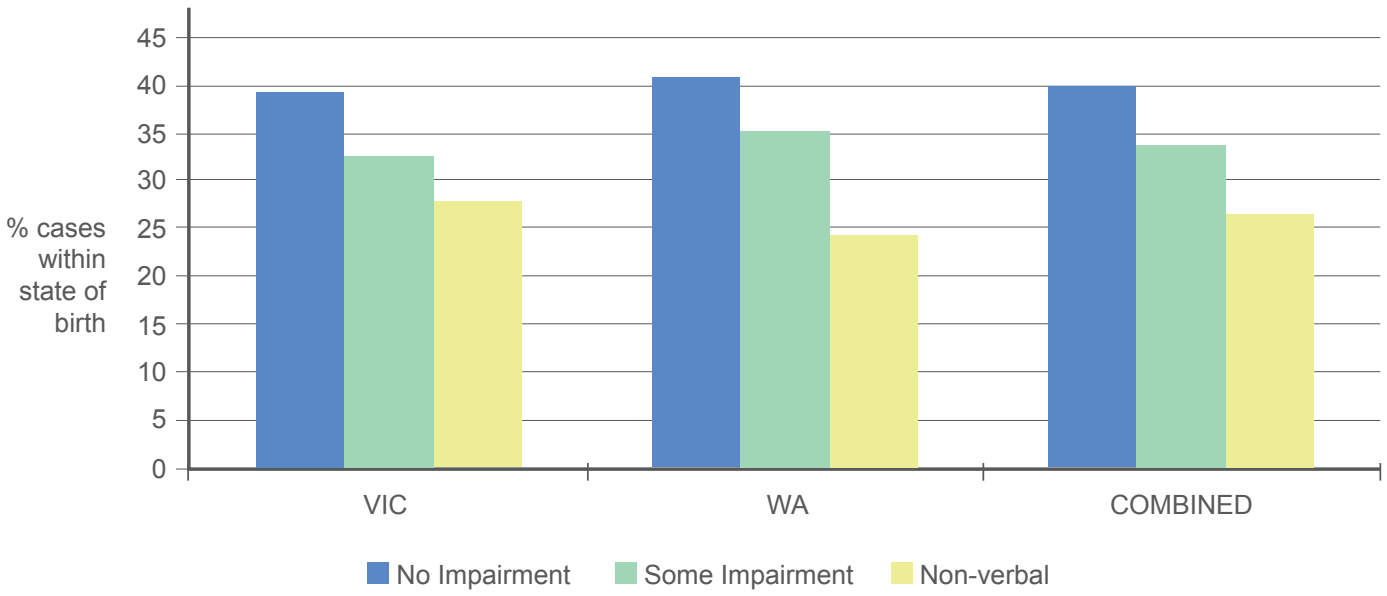
Speech

Table 19. Number and percentage of cerebral palsy cases by speech status and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.

	No impairment n (%)^	Some impairment n (%)^	Non-verbal n (%)^	TOTAL n	Status unknown n (%)
ACT	16 (40.0)	19 (47.5)	5 (12.5)	42	* (4.8)
NSW	199 (36.3)	221 (40.3)	128 (23.4)	570	22 (3.9)
NT	*(50)	*(50)	0 (0.0)	2	0 (0.0)
QLD	65 (50.4)	41 (31.8)	23 (17.8)	137	8 (5.8)
SA	135 (47.7)	112 (39.6)	36 (12.7)	367	84 (22.9)
TAS	23 (62.2)	11 (29.7)	* (8.1)	38	*(2.6)
VIC	**435 (39.4)**	**360 (32.6)**	**310 (28.0)**	**1195**	**90 (7.5)**
WA	**266 (40.7)**	**228 (35.0)**	**159 (24.3)**	**702**	**49 (7.0)**
TOTAL	***1140***	***993***	***664***	***3053***	***261***
COMBINED VIC, WA	**701 (39.9)**	**588 (33.4)**	**469 (26.7)**	**1897**	**139 (7.3)**

* < 5 cases
(%)^ calculated by n/total n minus unknown n; provided to allow state/territory comparisons

Figure 18. Percentage of cerebral palsy cases by speech status and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.



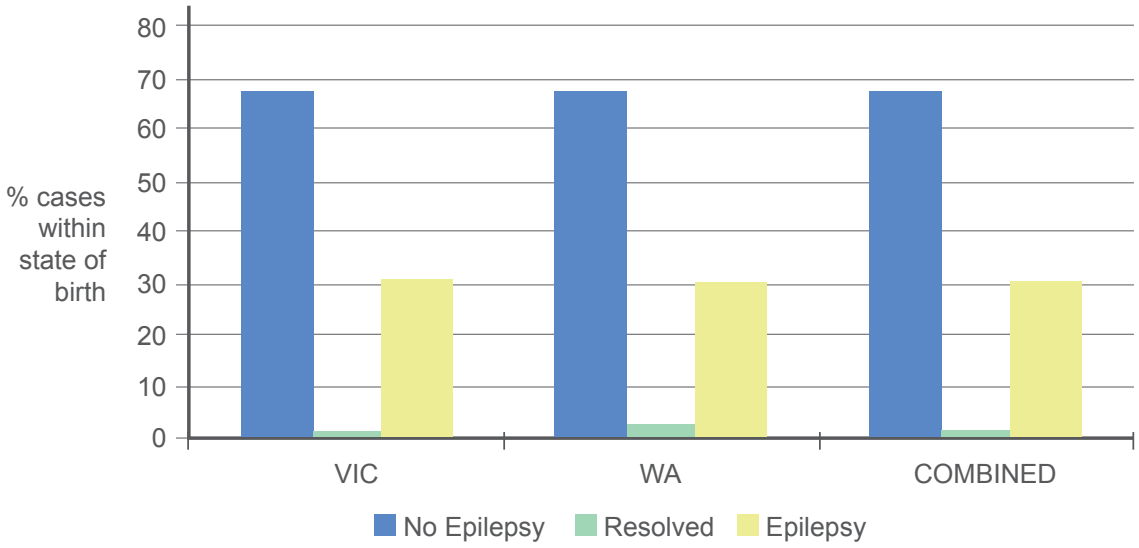
Epilepsy

Table 20. Number and percentage of cerebral palsy cases by presence/absence of epilepsy~ and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.

	No epilepsy n (%)^	Resolved# n (%)^	Epilepsy n (%)^	TOTAL n	Unknown n (%)
ACT	32 (80.0)	* (5.0)	6 (15.0)	42	* (4.7)
NSW	380 (69.9)	31 (5.7)	133 (24.4)	570	26 (4.6)
NT	* (50.0)	0 (0.0)	* (50.0)	2	0 (0.0)
QLD	96 (72.8)	* (3.0)	32 (24.2)	137	5 (3.6)
SA	177 (68.3)	24 (9.3)	58 (22.4)	367	108(29.4)
TAS	28 (75.7)	* (10.8)	5 (13.5)	38	*
VIC	**791 (67.6)**	**15 (1.3)**	**364 (31.1)**	**1195**	**25 (2.1)**
WA	**459 (67.8)**	**14 (2.1)**	**204 (30.1)**	**702**	**25 (3.6)**
TOTAL	***1964***	***92***	***803***	***3053***	***194***
COMBINED VIC, WA	**1250 (67.7)**	**29 (1.6)**	**568 (30.7)**	**1897**	**50 (2.6)**

* < 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/total n minus unknown n; provided to allow state/territory comparisons

Figure 19. Percentage of cerebral palsy cases by presence/absence of epilepsy~ and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.



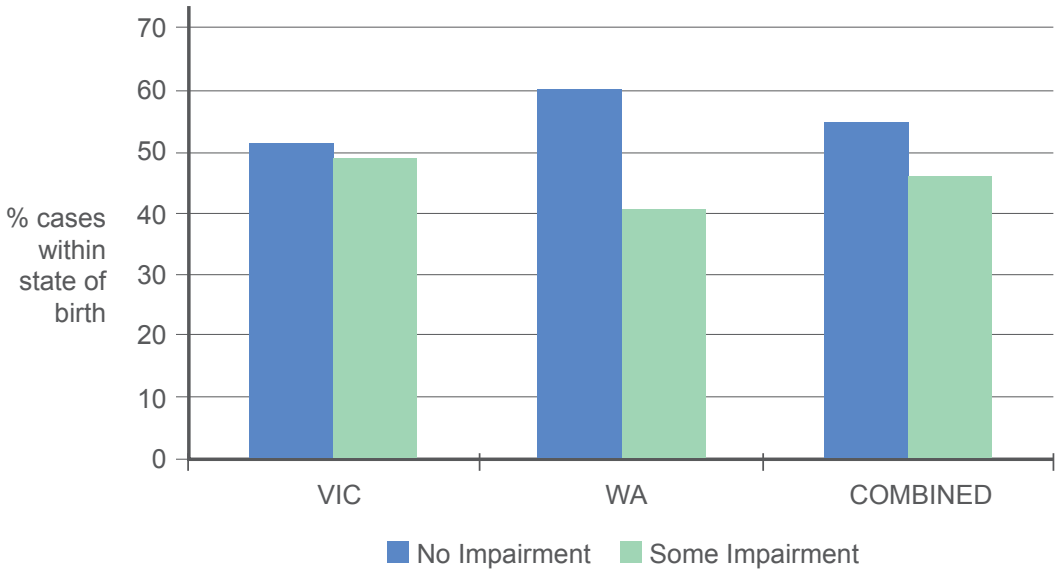
Intellectual impairment

Table 21. Number and percentage of cerebral palsy cases by level of intellectual impairment and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.

	No impairment n (%) ^	Probably greater than borderline impairment: severity uncertain n (%)^	Mild impairment n (%)^	Moderate impairment n (%)^	Severe-profound impairment n (%)^	TOTAL n	Unknown n (%)
ACT	20 (52.6)	5 (13.2)	6 (15.8)	5 (13.2)	* (5.3)	42	* (9.5)
NSW	248 (48.8)	64 (12.6)	64 (12.6)	76 (15.0)	56 (11.0)	570	62 (10.9)
NT	* (50.0)	0 (0.0)	* (50.0)	0 (0.0)	0 (0.0)	2	0 (0.0)
QLD	78 (63.4)	13 (10.6)	13 (10.6)	11 (8.9)	8 (6.5)	137	14 (10.2)
SA	165 (63.7)	7 (2.7)	39 (15.1)	22 (8.5)	26 (10.0)	367	108 (29.4)
TAS	20 (57.1)	* (2.9)	7 (20.0)	6 (17.1)	* (2.9)	38	* (7.9)
VIC	**559 (50.9)**	**163 (14.9)**	**137 (12.5)**	**98 (8.9)**	**140 (12.8)**	**1195**	**98 (8.2)**
WA	**401 (59.5)**	**59 (8.9)**	**59 (8.8)**	**66 (9.8)**	**88 (13.1)**	**702**	**29 (4.1)**
TOTAL	***1492***	***312***	***326***	***284***	***321***	***3053***	***318***
COMBINED VIC, WA	**960 (54.3)**	**222 (12.5)**	**196 (11.0)**	**164 (9.3)**	**228 (12.9)**	**1897**	**127 (6.7)**

* < 5 cases
(%)^ calculated by n/total n minus unknown n; provided to allow state/territory comparisons

Figure 20. Percentage of cerebral palsy cases by level of intellectual impairment and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.



In this cohort the combined data indicate that associated impairments were common for children with cerebral palsy. At the age of five: 30.7% had epilepsy; 45% had an intellectual impairment; 60% had a speech impairment; 37% had a vision impairment and 12% had a hearing impairment. More than 50% had more than one associated impairment.

RESULTS

Part 3:
Post-neonatally acquired cerebral palsy

Prevalence of cerebral palsy for cases where there is an identified post-neonatal cause

Table 22. Cerebral palsy cases by identified post-neonatal (PNN) cause and state/territory of birth (1993-2003).

	PNN acquired cases n (%)	All CP cases	Live births	Prevalence OF PNN cases per 10,000 live births
ACT	7 (14.3)	49	46372	-
NSW	52 (8.4)	622	955471	-
NT	* (0.0)	2	40383	-
QLD	9 (6.2)	146	518563	-
TAS	* (2.6)	39	67747	-
SA	**13 (3.4)**	**380**	**204204**	**0.64**
VIC	**58 (4.6)**	**1253**	**689802**	**0.84**
WA	**56 (7.4)**	**758**	**276318**	**2.02**
TOTALS SA, VIC, WA	***127 (5.3)***	***2391***	***1170324***	***Combined Prevalence: 1.08***

* < 5 cases

In this cohort the combined data indicate the prevalence for post-neonatally acquired cerebral palsy was estimated to be 1.08 per 10,000 live births.

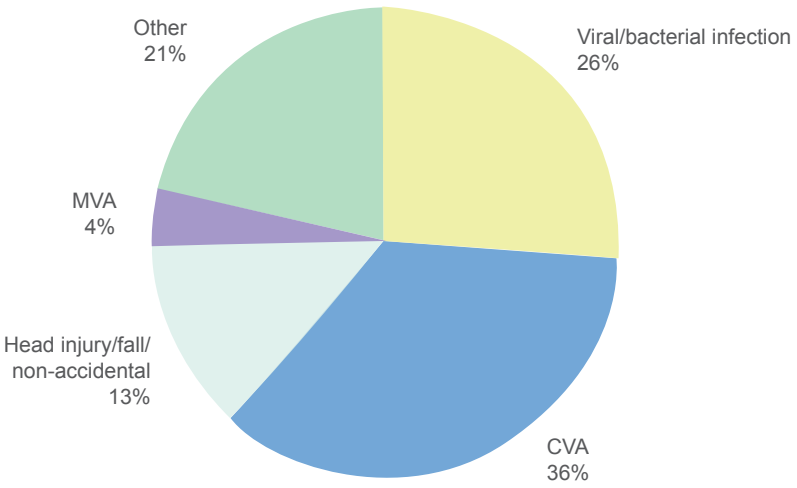
Post-neonatal cause

Table 23. Number and percentage of cerebral palsy cases by identified post-neonatal cause, born in South Australia, Victoria and Western Australian (1993-2003).

Post-Neonatal cause	TOTAL CASES SA, VIC, WA COMBINED n (%)
Viral/bacterial infection unspecified	33 (26.0)
CVA# associated with surgery	8 (6.3)
CVA# associated with cardiac complications	7 (5.5)
Spontaneous/other CVA#	30 (23.6)
Fall	4 (3.1)
Non-accidental Injury	11 (8.7)
Other head injury	2 (1.6)
Near drowning	3 (2.4)
Apparent life threatening event	3 (2.4)
Post-immunisation	3 (2.4)
Post-seizure	5 (3.9)
Peri-operative hypoxia	2 (1.6)
Other post-natal event	11 (8.7)
Motor vehicle accident	5 (3.9)
TOTAL	***127***

* < 5 cases
CVA# Cerebro-vascular accident

Figure 21. Percentage of cerebral palsy cases by identified post-neonatal cause, born in South Australia, Victoria and Western Australian (1993-2003).



In this cohort the combined data indicate the predominant post-neonatal cause of cerebral palsy is a CVA being either spontaneous, associated with surgery or with cardiac complications.

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APPENDIX A -
INFORMATION AND CONTACT DETAILS OF THE CONTRIBUTING STATE AND TERRITORY CEREBRAL PALSY REGISTERS

Table 1. State and territory establishment dates and consent types.

Name	Date of Establishment	Custodian Organisation	Type of Consent Required	Contactable for Future Research
NSW and ACT Cerebral Palsy Register	2005	The Cerebral Palsy Institute, a wholly owned subsidiary of The Spastic of New South Wales	IC	Yes
Northern Territory Cerebral Palsy Register	2008	Department of Health and Families	IC	Yes
Queensland Cerebral Palsy Register	2006	Cerebral Palsy League of Queensland	IC	Yes
The South Australian Cerebral Palsy Register	1998	Children, Youth and Women's Health Service	L, IC	Yes
Tasmanian Cerebral Palsy Register	2008	Menzies Research Institute	IC	Yes
Victorian Cerebral Palsy Register	1986	Murdoch Childrens Research Institute / Royal Children's Hospital, Melbourne	E, IC,O	Yes (Approximately 80%)
Western Australia Cerebral Palsy Register	1977	Telethon Institute for Child Health Research	E	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

The Cerebral Palsy Institute, a wholly owned subsidiary of The Spastic of New South Wales

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 Institute
The University of Notre Dame Australia
PO Box 560
Darlinghurst 1300
E smcintyre@tscnsw.org.au
T 02 8204 4492

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

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

Carmen Ewens
Royal Darwin Hospital
Rocklands Dr
PO Box 41326 Casuarina, 0811
Tiwi NT 0810
Australia
E carmen.ewens@nt.gov.au
T 08 8922 8338

Purpose: The main aims of the cerebral palsy 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 live in or were born in Queensland who have cerebral palsy.

Michael deLacy
QCPR
PO Box 386
Fortitude Valley
Brisbane Qld 4006
Australia
E mdelacy@cplqld.org.au
T 07 3358 8002

Purpose: Determine the number, locations and general abilities of the population of people with cerebral palsy in QLD for use by government and non-government agencies in service planning. Provide a population resource for intervention trials. Contribute to investigations into causes and prevention of cerebral palsy.

The South Australian Cerebral Palsy Register

(part of the South Australian Birth Defects Register)
Children, Youth and Women's Health Service

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

Phillipa van Essen / Catherine Gibson
Children, Youth and Women's Health Service
72 King William Road
North Adelaide
Adelaide SA 5006
Australia
E cywhs.sabdr@health.sa.gov.au
T 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

Menzies Research Institute

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.

Julie Bunyard
Menzies Research Institute
Private Bag 23
Hobart Tasmania 7001
Australia
E tascpregister@menzies.utas.edu.au
T 03 6226 4717

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 cerebral palsy in the state. The register also aims to facilitate research into the causes, prevention and treatment of cerebral palsy.

The 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
E sue.reid@mcri.edu.au
T 03 9345 4807

Purpose: (1) To determine the frequency and describe the characteristics of cerebral palsy in Victoria (2) To enable research into aetiology (3) To select cohorts for intervention and other studies.

Western Australian Cerebral Palsy Register

Telethon Institute for Child Health Research

Target population: All individuals from birth-year 1956 who have cerebral palsy 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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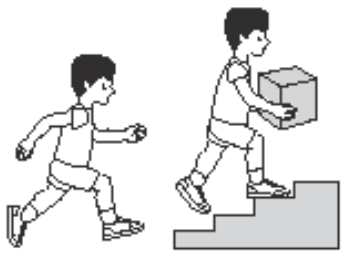
Purpose: (1) To monitor trends in cerebral palsy and identify areas of concern for future investigation (2) To conduct population based epidemiological studies of the various cerebral palsy subgroups, particularly to elucidate causes (3) To evaluate changes in antenatal, obstetric and neonatal care in relation to cerebral palsy as an index of neurological outcome (4) To identify cerebral palsy as an outcome in other study populations (5) To aid in the planning of services for individuals with cerebral palsy by providing distribution of cerebral palsy in WA by age, severity, geographical area, etc to service organisations (6) To contribute WA cerebral palsy data to the Australian Cerebral Palsy Register

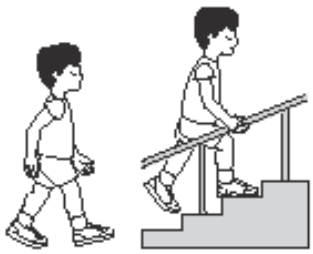
APPENDIX B -
GROSS MOTOR FUNCTION SCALE - DESCRIPTORS AND ILLUSTRATIONS

GMFCS for children aged 6–12 years: Descriptors and illustrations



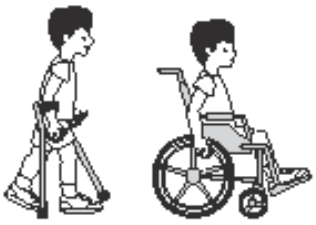
GMFCS Level I

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.



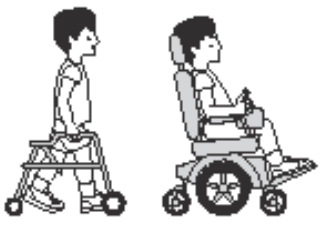
GMFCS Level II

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.



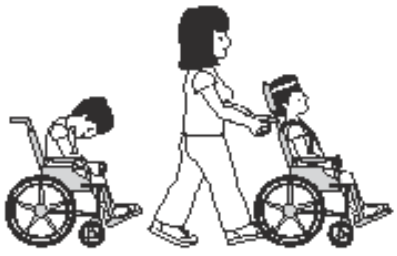
GMFCS Level III

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.



GMFCS Level IV

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.



GMFCS Level V

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.

Footnote *GMFCS by Palisano et al.*

Palisano RJ, Rosenbaum P, Walter S, Russell D, Wood E, Galuppi B. Development and reliability of a system to classify gross motor function in children with cerebral palsy. Dev Med Child Neurol. 1997;45:113–120. Illustrated by Kerr Graham and Bill Reid, The Royal Children's Hospital, Melbourne.

APPENDIX C -
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CP Register

Piecing together the facts on cerebral palsy