

Australian Cerebral Palsy Register Report 2009

Birth Years 1993-2003



Cerebral Palsy
INSTITUTE

www.CPInstitute.com.au



Piecing together the facts on cerebral palsy
<https://secure.cpregister-aus.com.au>

AUTHORS

The Australian Cerebral Palsy Register Group consists of representatives from each state and territory register.

Australian Capital Territory

Rebecca Kippen

New South Wales

Nadia Badawi, Shona Goldsmith, Sarah McIntyre, Iona Novak, Paul Novak, Hayley Smithers-Sheedy, Katherine Swinburn

Northern Territory

Keith Edwards, Carmen Ewens, Cheryl Ingham

Queensland

Michael deLacy, Christalla Louca

South Australia

Catherine Gibson, Eric Haan, Rosie Rice, Heather Scott, Phillipa van Essen

Tasmania

Julie Bunyard, Peter Flett, Alison Venn

Victoria

Anna Lanigan, Tess Lioni, Dinah Reddihough, Sue Reid

Western Australia

Eve Blair, Jan De Groot, Noula Gibson, Sarah Love, Linda Watson



Recommended Citation:

ACPR Group, Report of the Australian Cerebral Palsy Register, Birth Years 1993-2003, Dec 2009.

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.





FOREWORD



Karin B. Nelson, MD is a child neurologist, scientist emerita 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 cerebrovascular accident (35%) being either spontaneous, associated with surgery or with complications of cardiac defects.



INDEX

| | |
|---|-----------|
| About cerebral palsy | 10 |
| What is the Australian Cerebral Palsy Register (ACPR)? | 11 |
| Aims of the ACPR | 12 |
| Ethics | 12 |
| Current projects | 12 |
| Methods | 13 |
| Cohort | 13 |
| Inclusion/exclusion criteria | 13 |
| Denominator data | 13 |
| Eligibility criteria for combining datasets | 13 |
| Results | 13 |
| Results | |
| Results Part 1: All cerebral palsy cases | 15 |
| Number and percentage pre/perinatally acquired vs postneonatally acquired cases | 16 |
| Results Part 2: Pre/perinatally acquired cerebral palsy | 17 |
| Cohort of cases of cerebral palsy | 19 |
| Prevalence | 20 |
| Sex | 22 |
| Maternal age at time of delivery | 23 |
| Maternal country of birth | 24 |
| Indigenous status of mother | 25 |
| Gestational age at delivery | 26 |
| Birth weight | 27 |
| Plurality | 28 |
| Assisted conception | 29 |
| Pre/perinatal causes of cerebral palsy | 30 |
| Predominant motor type | 31 |
| Topographical pattern of spasticity | 32 |
| Gross motor function | 33 |
| Birth defects | 34 |
| Associated disorders or impairments at 5 years of age | 35 |
| Vision | 35 |
| Hearing | 36 |
| Speech | 37 |
| Epilepsy | 38 |
| Intellectual impairment | 39 |
| Results Part 3: Post-neonatally acquired cerebral palsy | 40 |
| Prevalence | 41 |
| Cases by identified post-neonatal cause | 42 |
| References | 43 |
| Appendices | 44 |
| Appendix A Information and contact details of the contributing state and territory cerebral palsy registers | 44 |
| Appendix B Gross Motor Function Classification System descriptors and illustrations 6-12 years | 47 |
| Appendix C References generated by contributing state and territory cerebral palsy registers | 48 |

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?

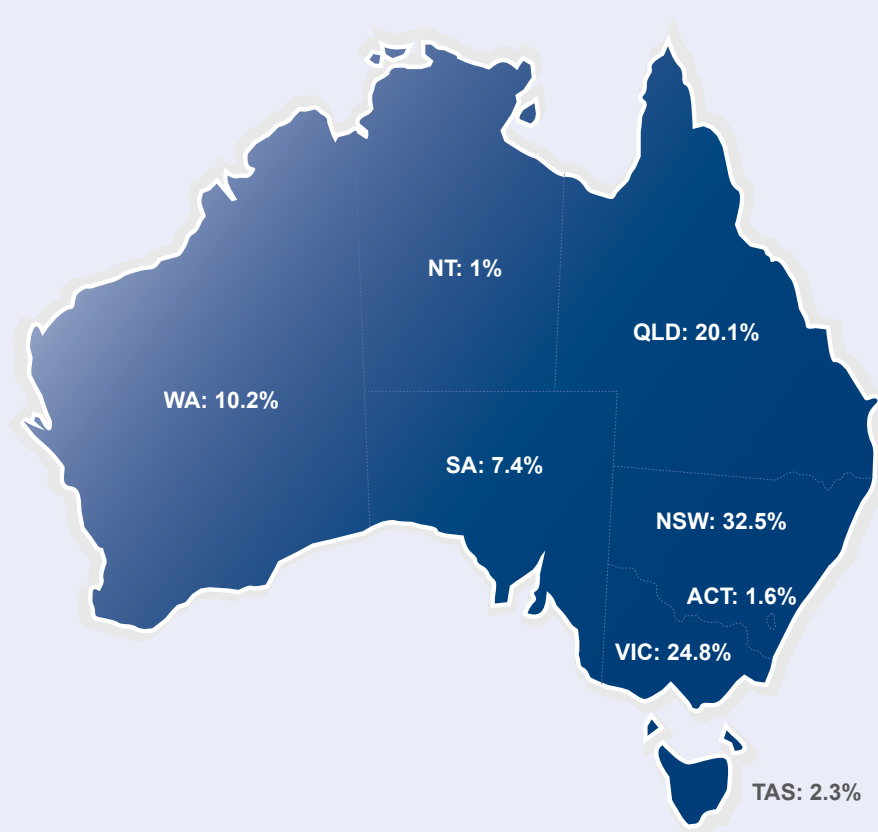
The ACPR is an electronic database of data uploaded from the cerebral palsy registers in each state and territory of Australia, from which client identifiers have been removed and replaced by a unique code in order to ensure privacy of data.

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: cpreregister@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: cpreregister@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

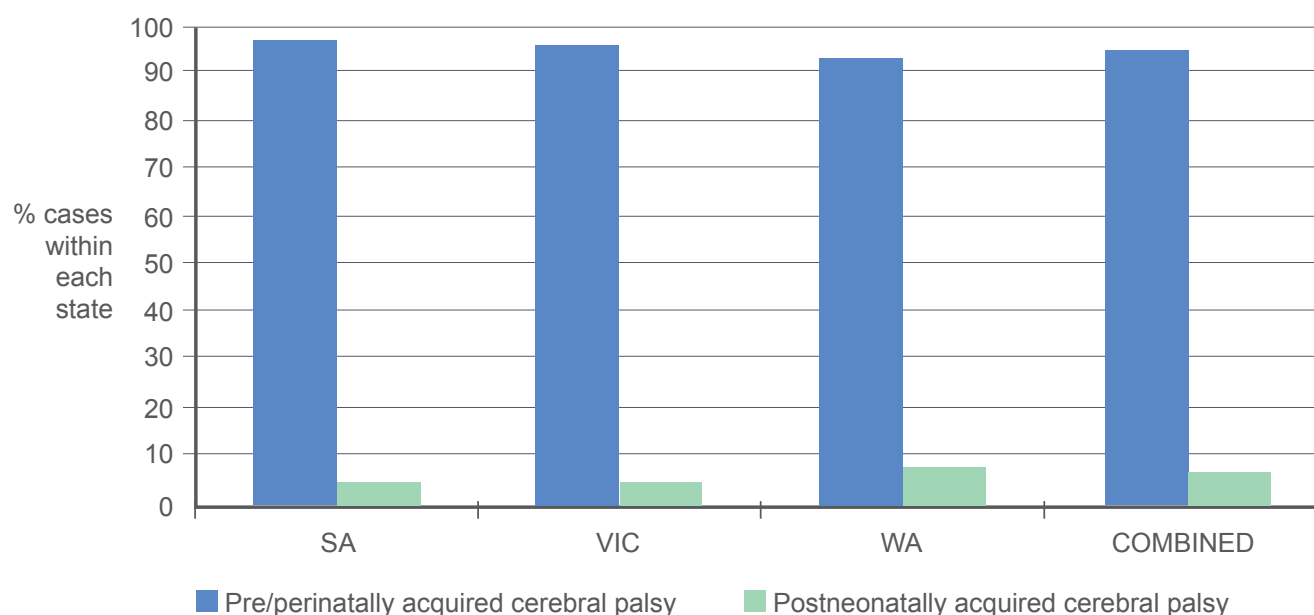
Table 1. Pre/perinatally and post-neonatally acquired cerebral palsy (CP) by state/territory of birth (1993-2003).

| | 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

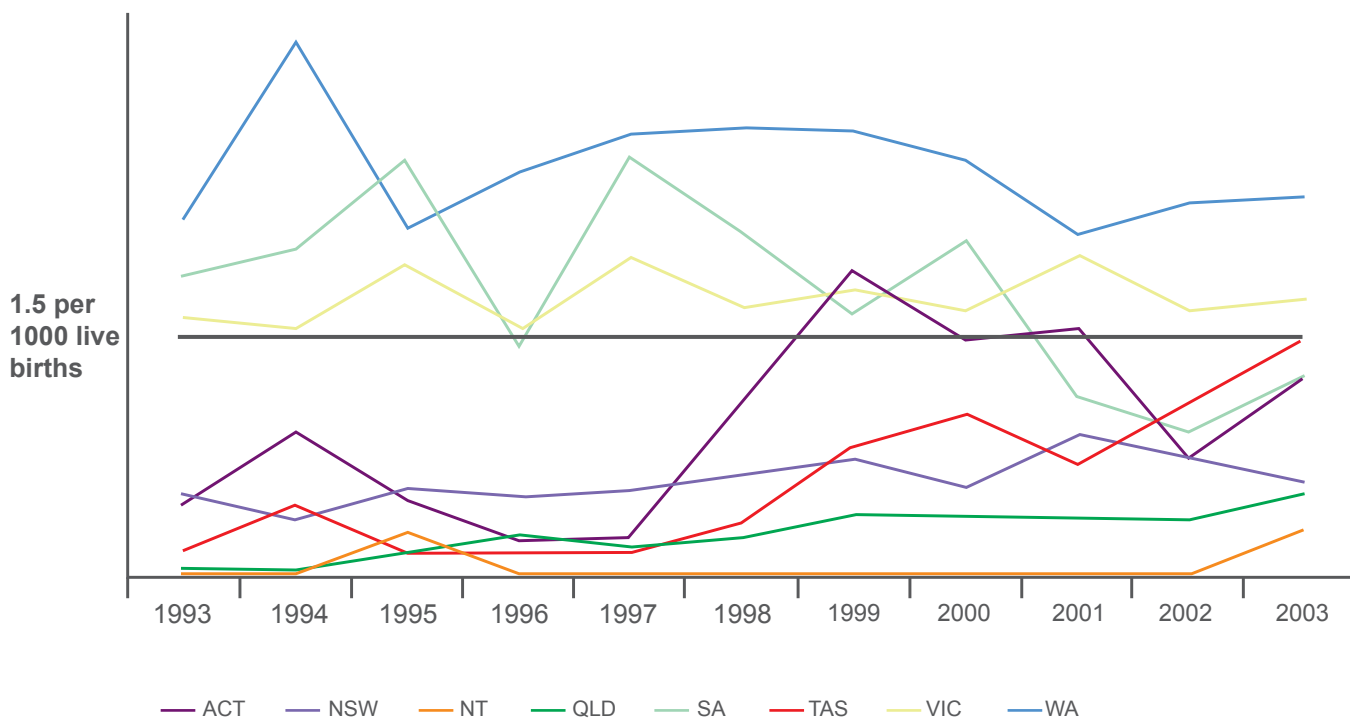
Prenatally or perinatally acquired cerebral palsy

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.

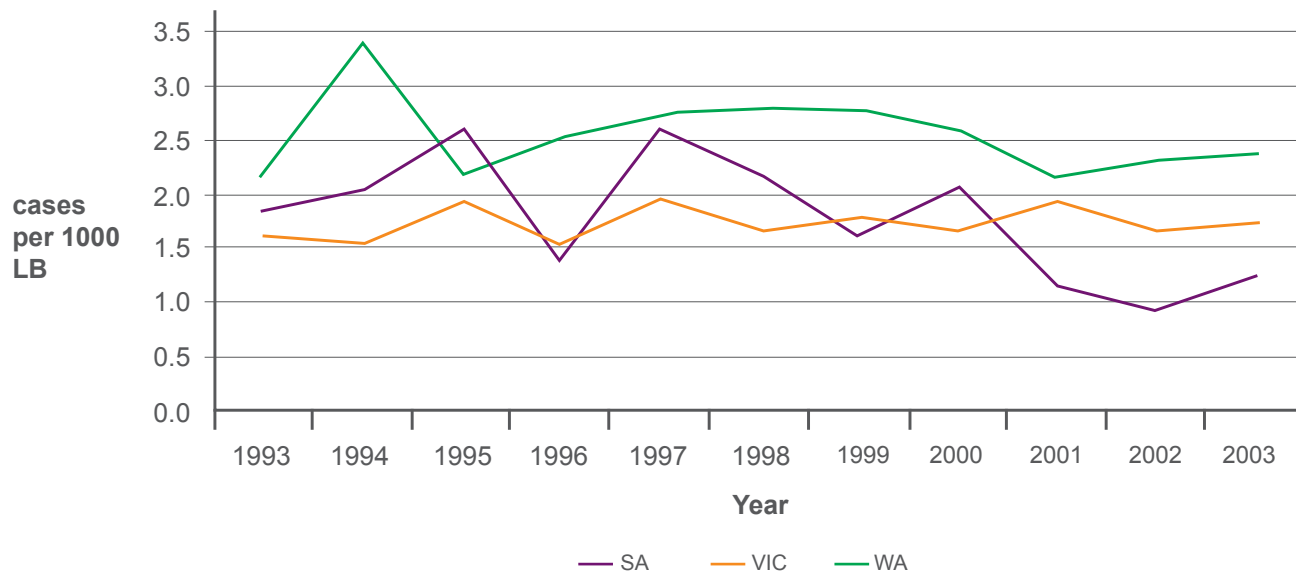


Figure 5. Total prevalence (95% confidence intervals) of cerebral palsy per 1000 live births by state (1993-2003), excluding cases with known post-neonatal causes.

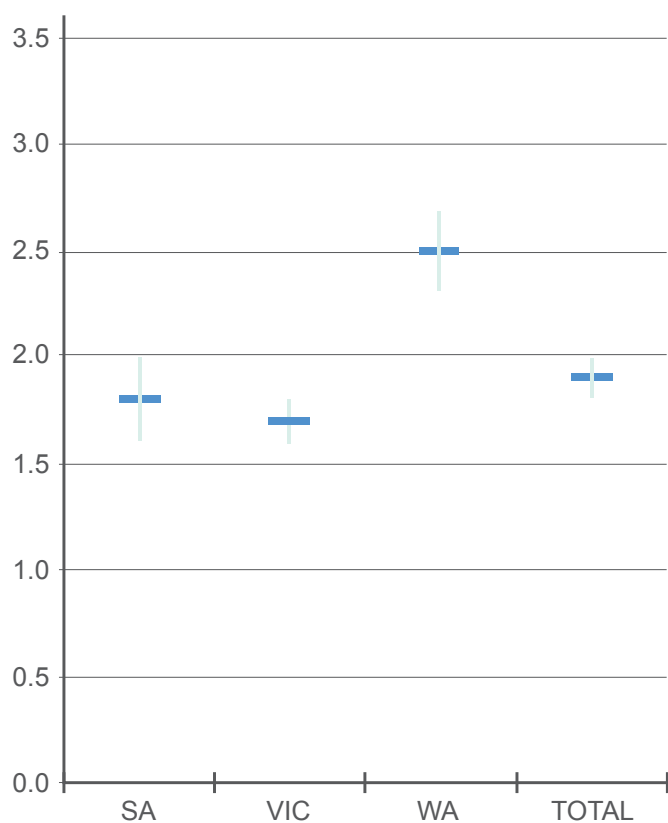


Table 3. Total prevalence of cerebral palsy (CP) per 1000 live births by state (1993 - 2003), excluding cases with known post-neonatal causes.

| | 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).

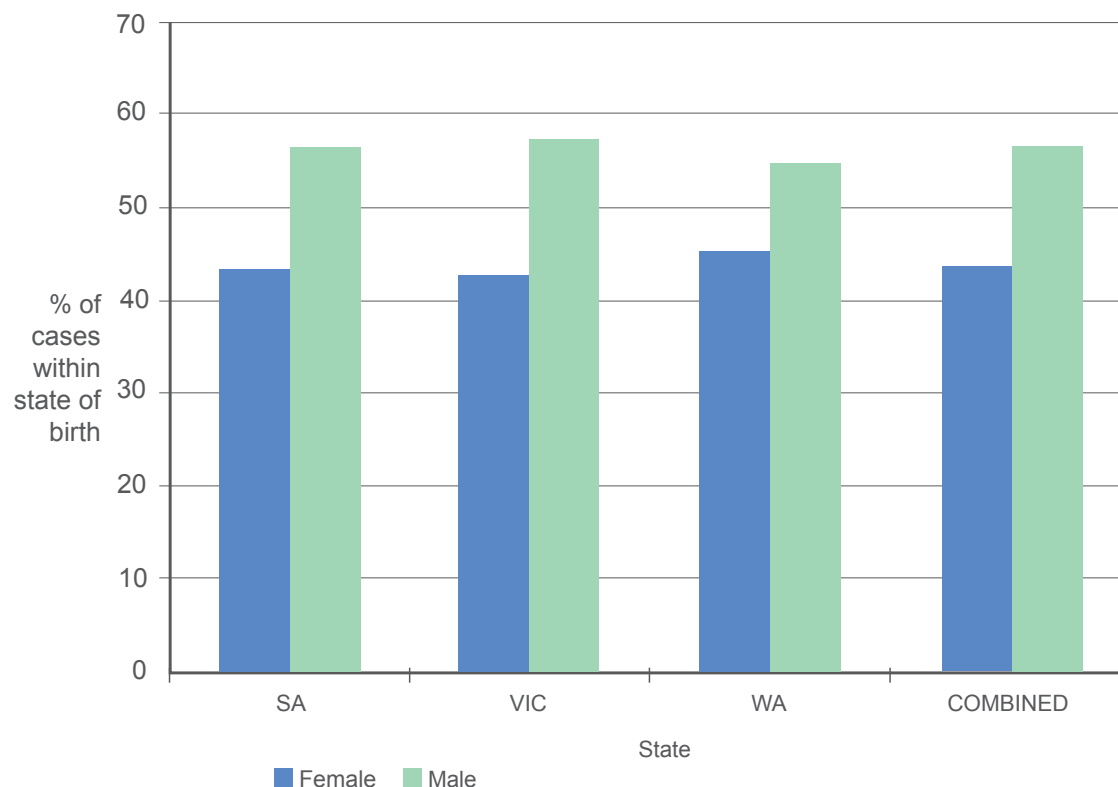
Sex

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.

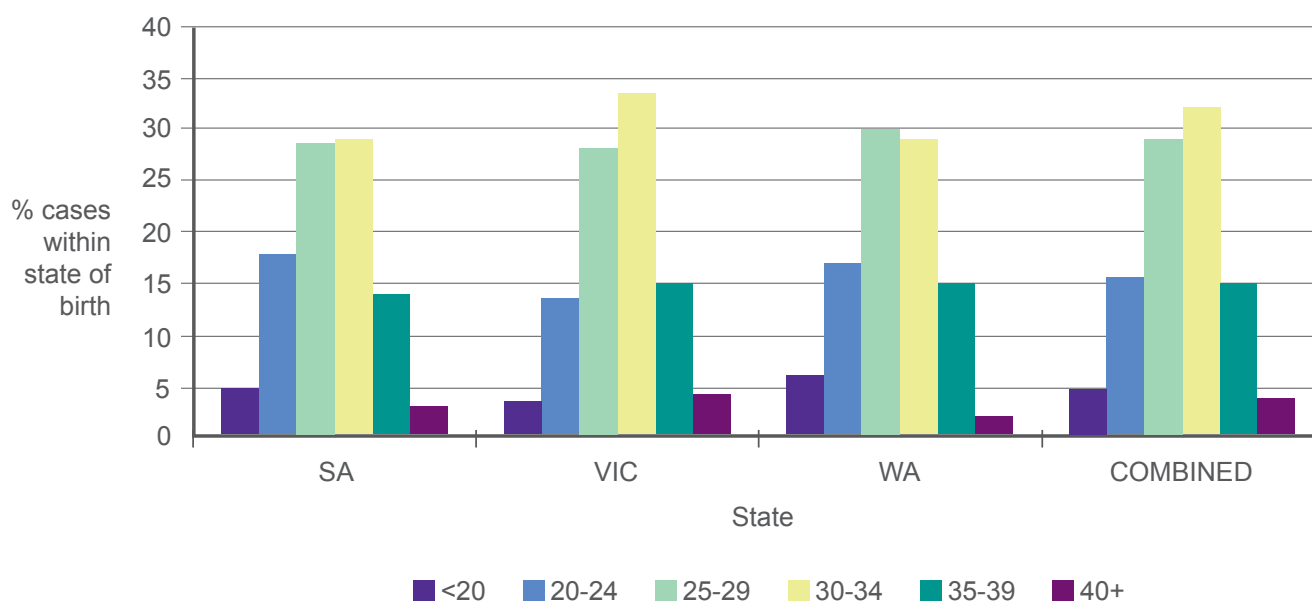
Table 5. Number and percentage of cerebral palsy cases by maternal age group in years at delivery and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.

| | <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]

Maternal country of birth

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 Antarctica 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

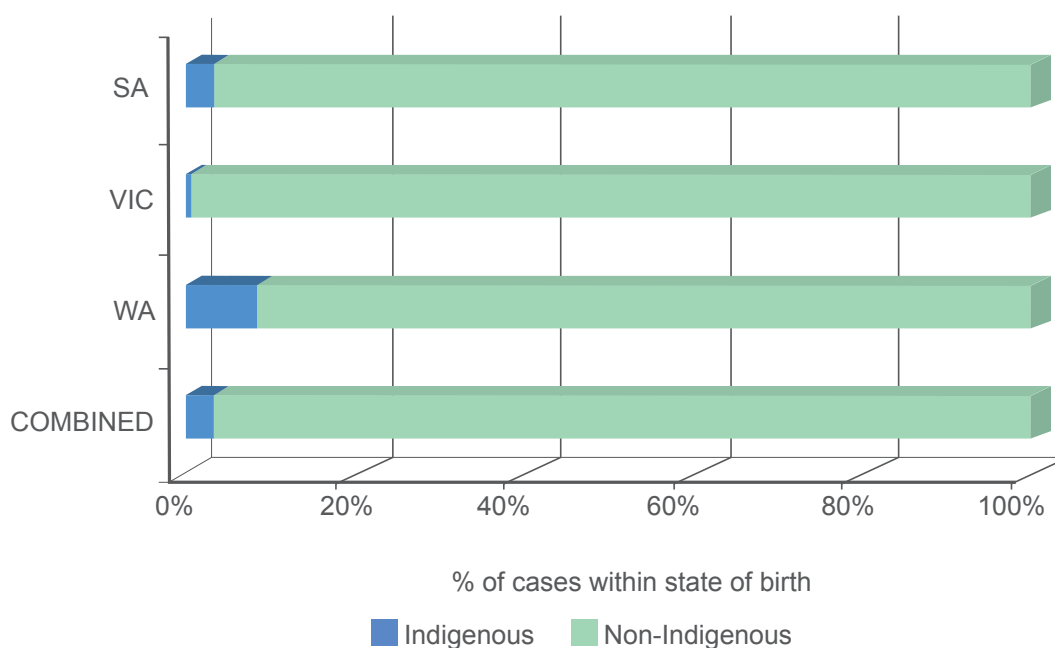
Table 7. Number and percentage of cerebral palsy cases by Indigenous status of mother and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.

| | 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

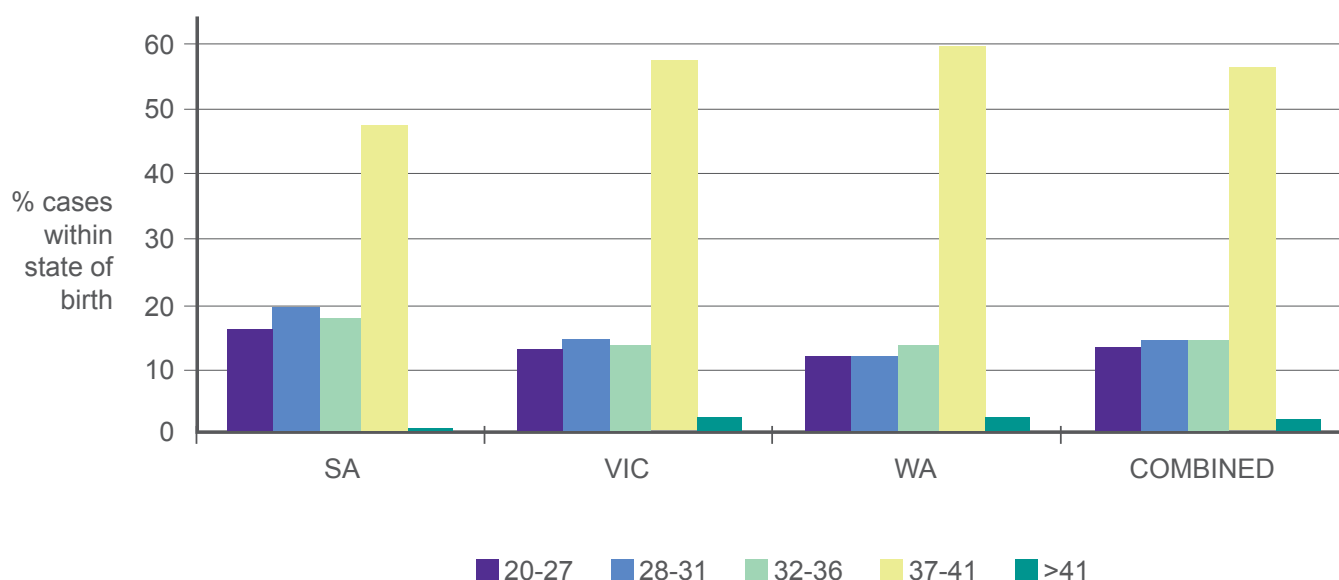
Table 8. Number and percentage of cerebral palsy cases by gestational age in weeks at delivery and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.

| | 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

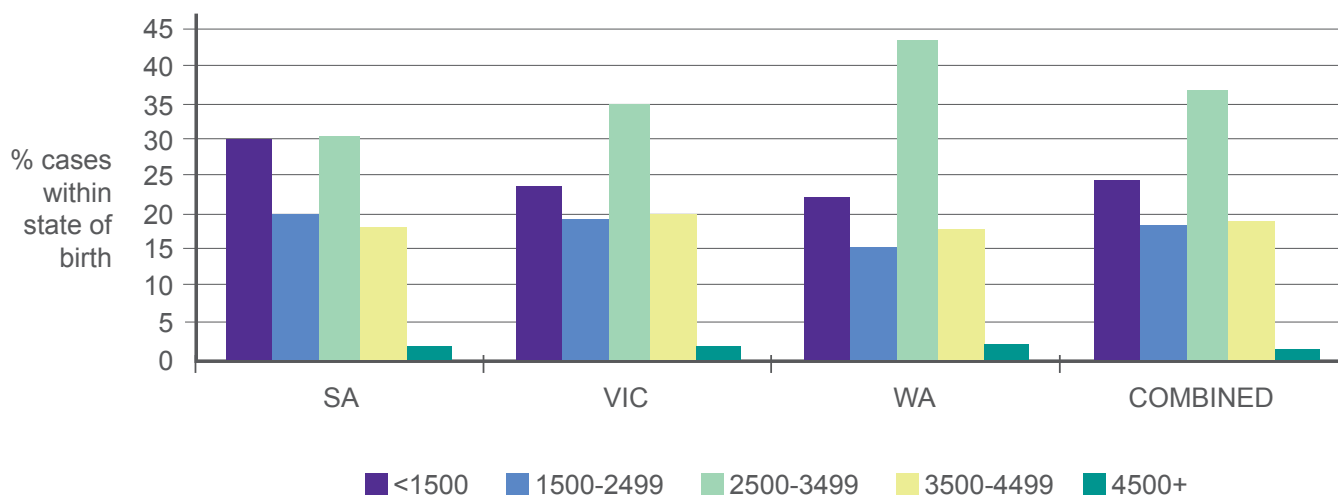
Table 9. Number and percentage of cerebral palsy cases by birth weight in grams and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.

| | <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

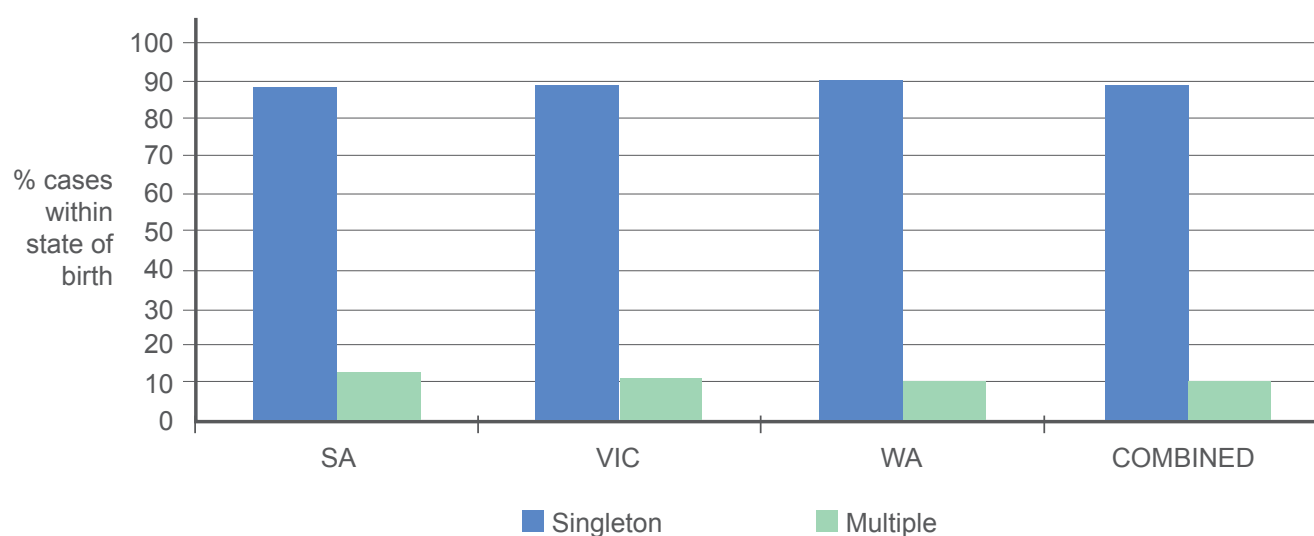
Table 10. Number and percentage of cerebral palsy cases by birth plurality and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.

| 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

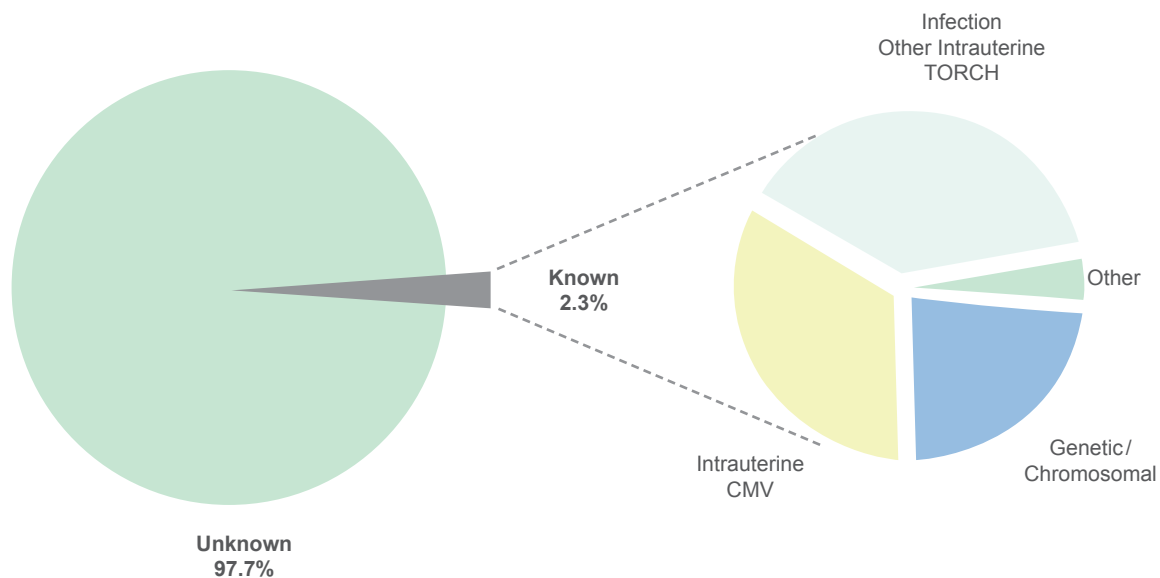
Table 12. Number and percentage of cerebral palsy cases by pre/perinatal cause and state/territory of birth (1993-2003).

| 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

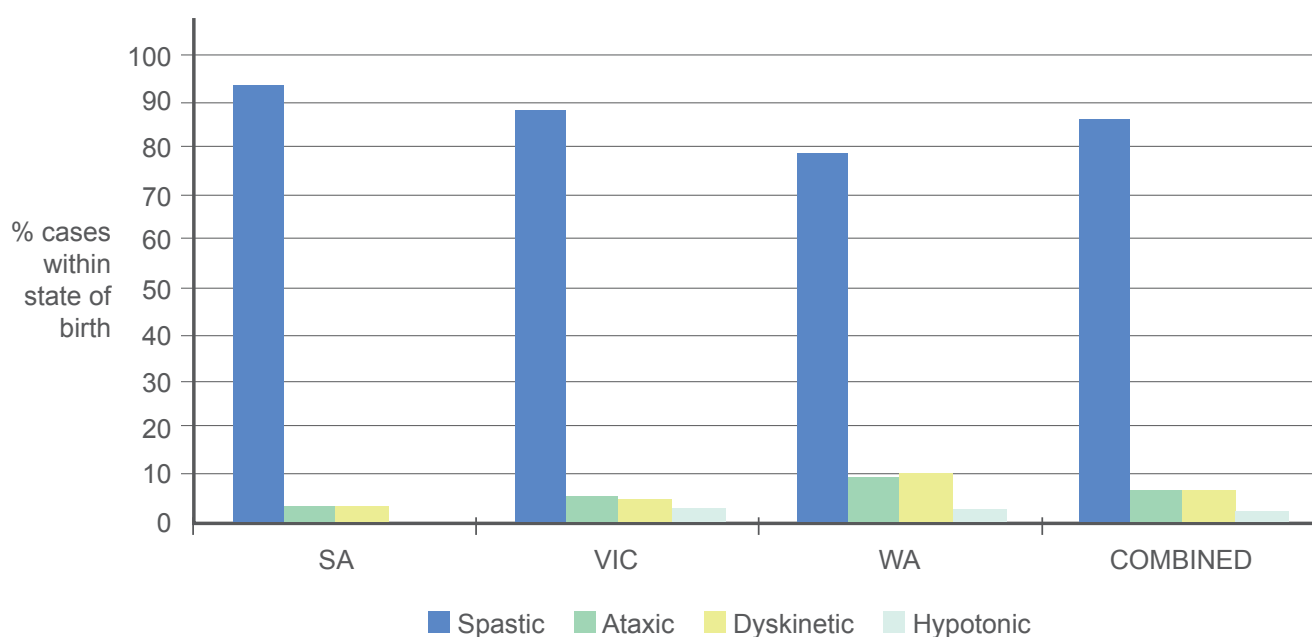
Table 13. Number and percentage of cerebral palsy cases by predominant motor type and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.

| | 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%)

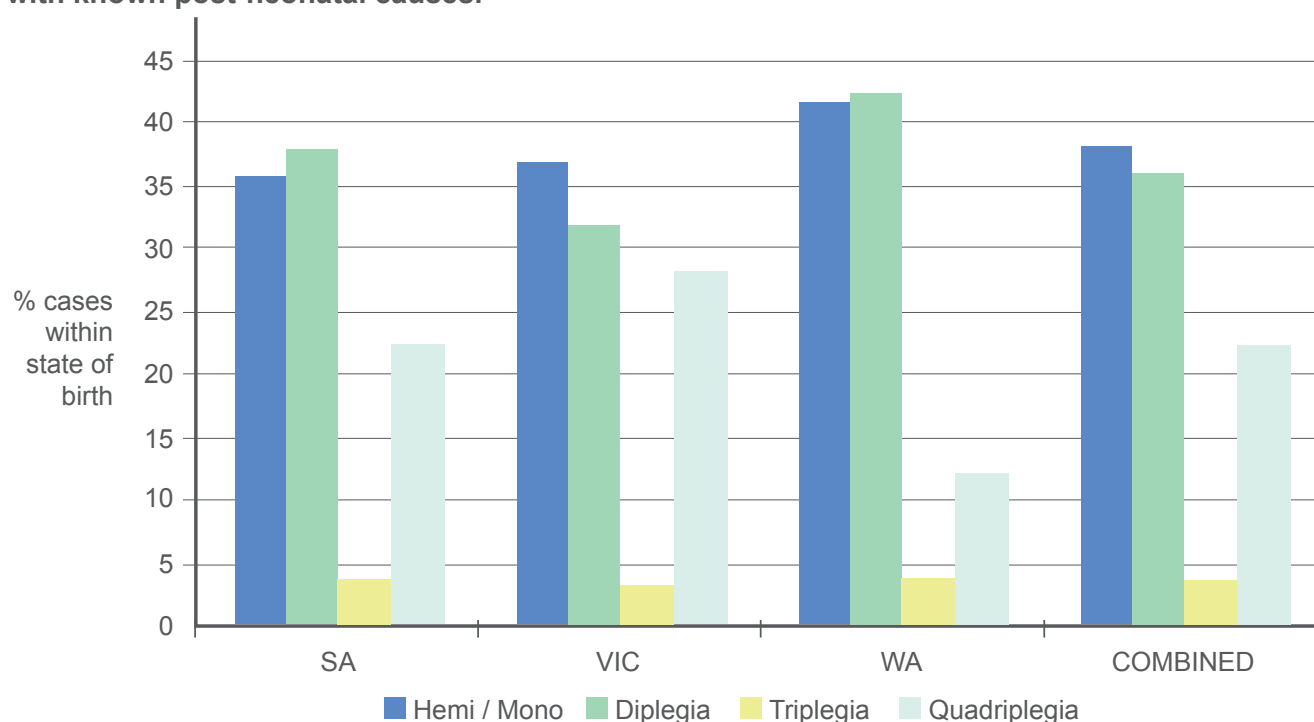
Topographical pattern of spasticity

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.

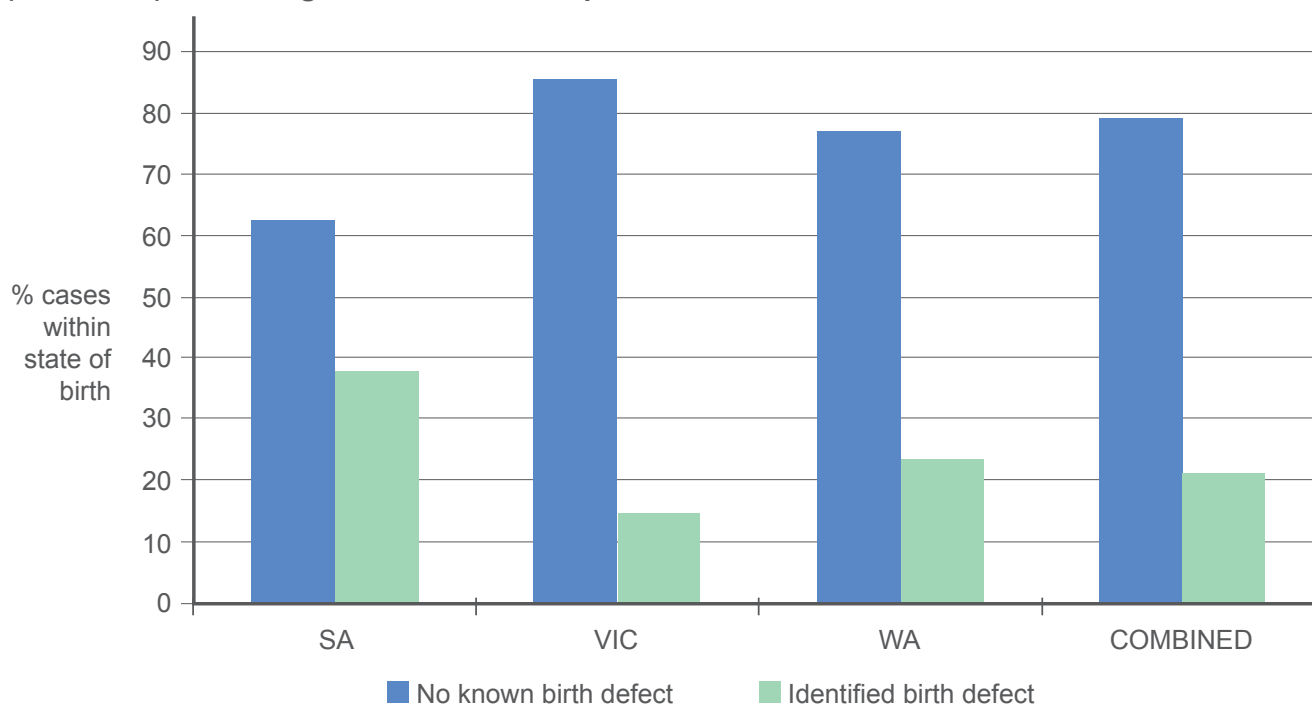
| | No known birth defect n (%)^ | Birth defect n (%)^ | TOTAL n | Unknown n (%) |
|---------------------------------|---------------------------------|------------------------|-------------|------------------|
| ACT | 34 (85.0) | 6 (15.0) | 42 | * (4.8) |
| NSW | 435 (82.7) | 91 (17.3) | 570 | 44 (7.7) |
| 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

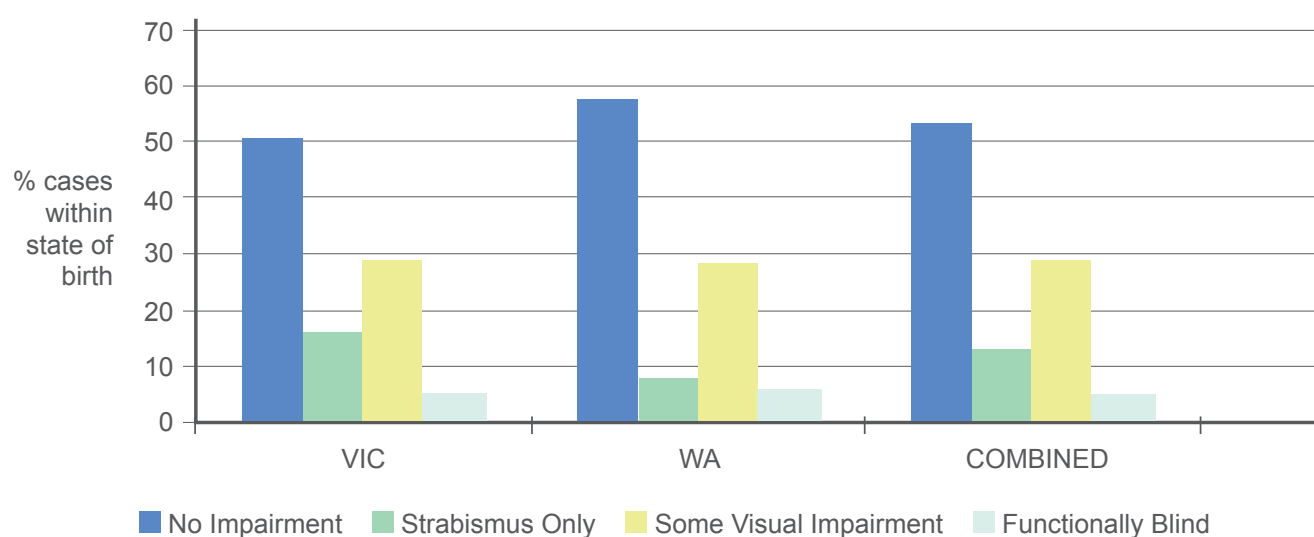
Table 17. Number and percentage of cerebral palsy cases by vision status and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.

| | 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

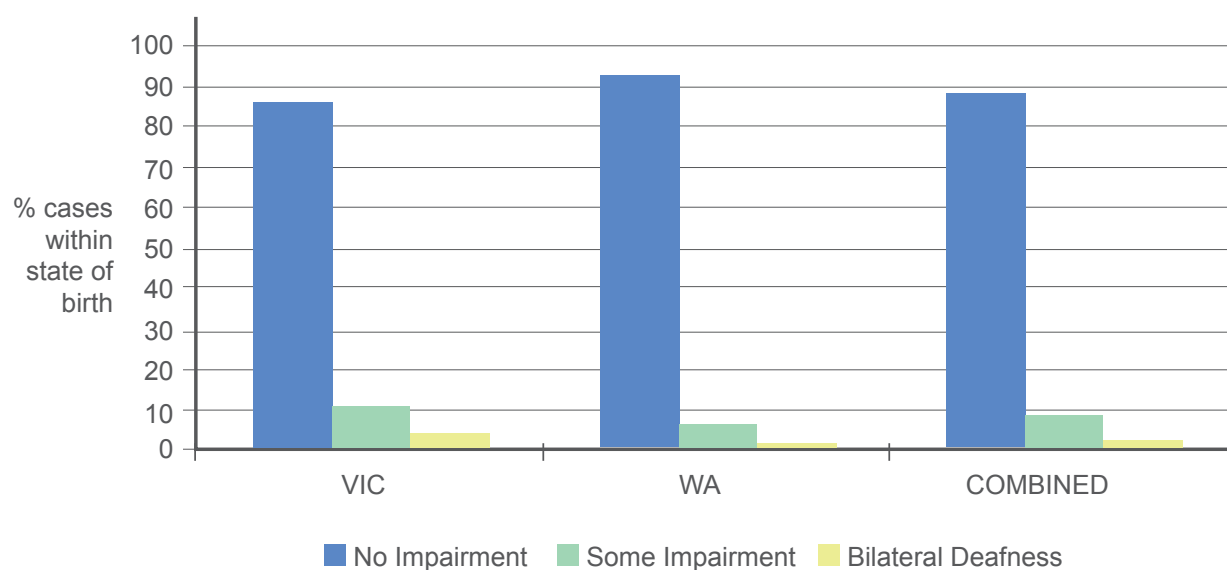
Table 18. Number and percentage of cerebral palsy cases by hearing status and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.

| | 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

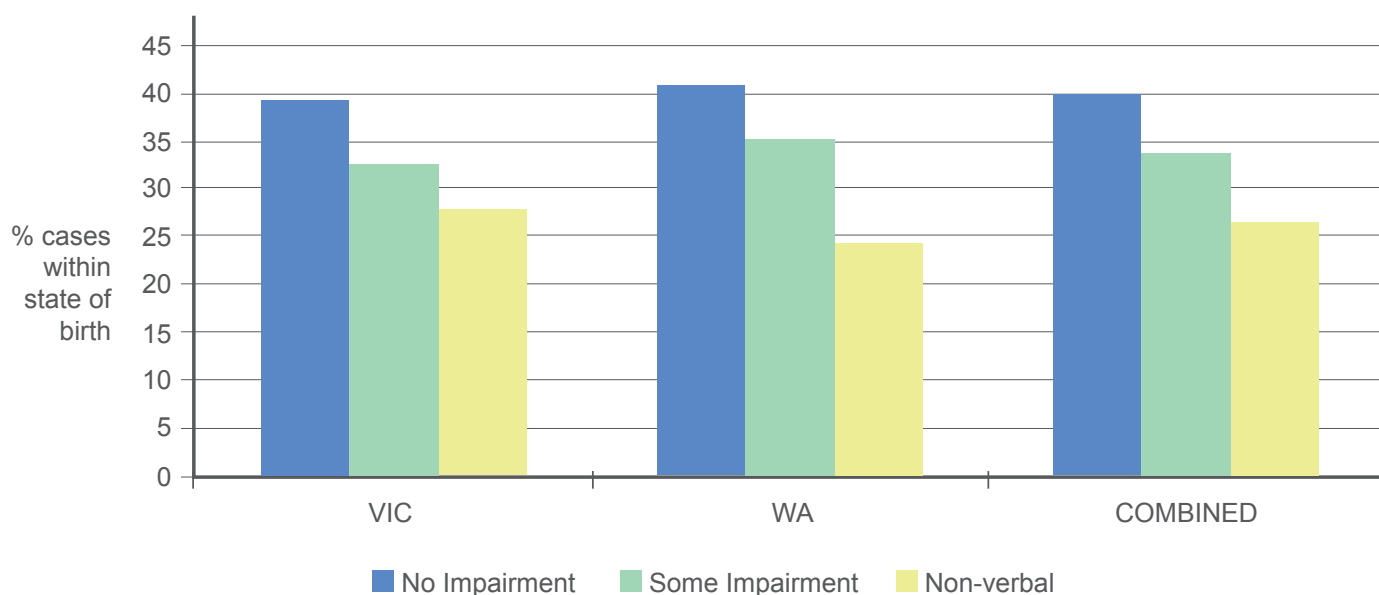
Table 19. Number and percentage of cerebral palsy cases by speech status and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.

| | 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) |

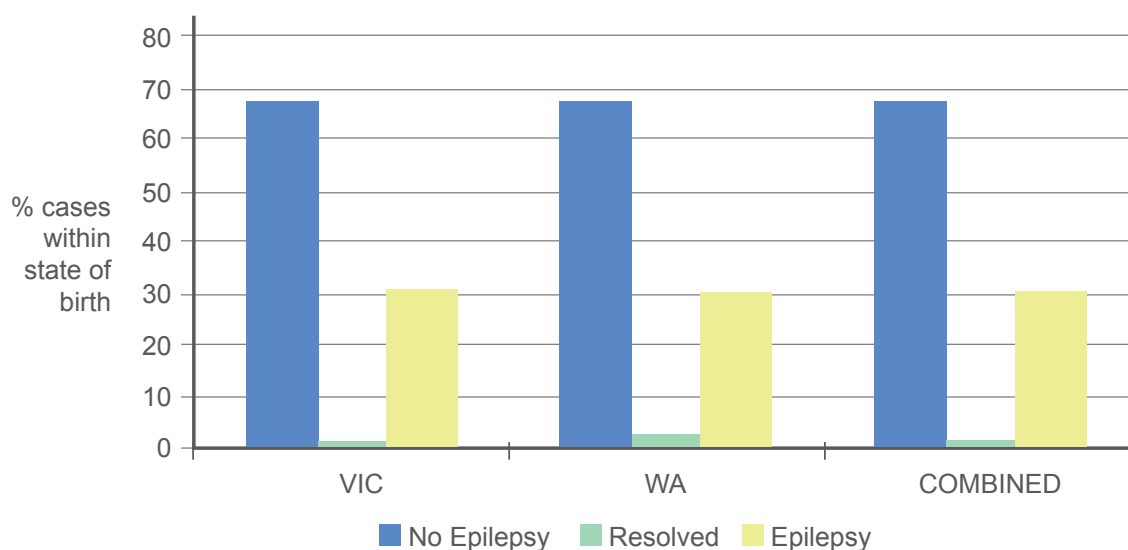
* < 5 cases

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

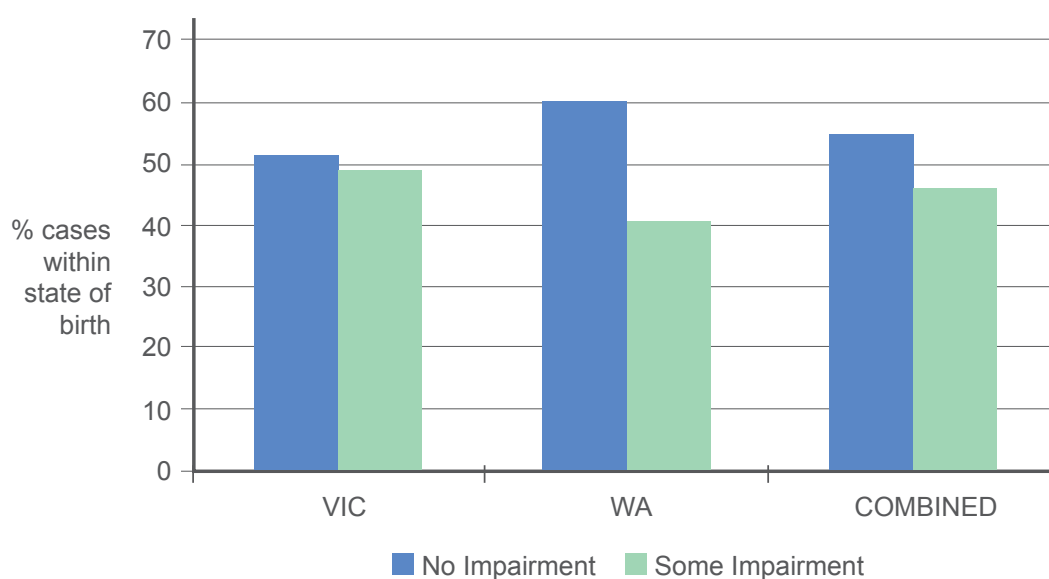
Table 21. Number and percentage of cerebral palsy cases by level of intellectual impairment and state/territory of birth (1993-2003), excluding cases with known post-neonatal causes.

| | 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

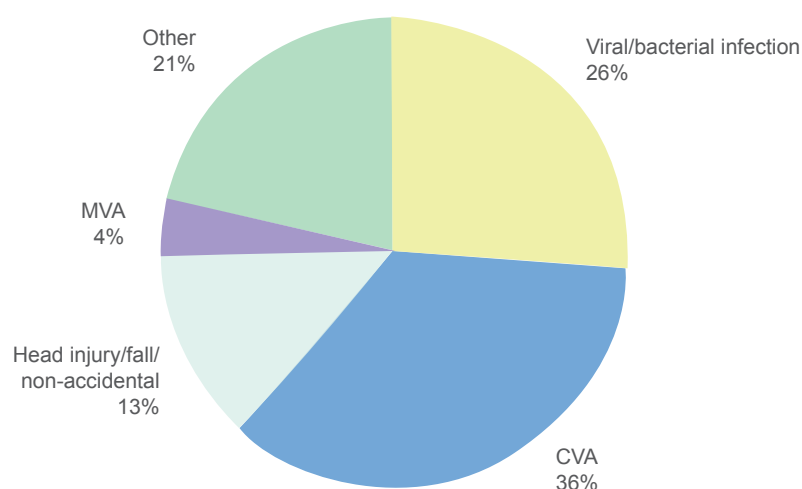
Table 23. Number and percentage of cerebral palsy cases by identified post-neonatal cause, born in South Australia, Victoria and Western Australian (1993-2003).

| 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.

REFERENCES

1. Stanley F, Blair E, Alberman E. *How common are the cerebral palsies?* , in *Cerebral Palsies: Epidemiology and Causal Pathways*. London: MacKeith Press, 2000:22-29.
2. Reddihough D, Collins K. *The epidemiology and causes of cerebral palsy*. *Aust J Physiother* 2003;**49**(1):7-12.
3. Rosenbaum P, Paneth N, Leviton A, Goldstein M, Bax M, Damiano D, Dan B, Jacobsson B. *A report: the definition and classification of cerebral palsy April 2006*. *Dev Med Child Neurol Suppl* 2007;**109**:8-14.
4. Smithers-Sheedy H, McIntyre, S, Watson, L, Yeargin-Allsop, M, Blair, E, Cans, C. *Report of the international survey of cerebral palsy registers and surveillance systems*: Cerebral Palsy Institute, 2009
5. *Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers. Surveillance of Cerebral Palsy in Europe (SCPE)*. *Dev Med Child Neurol* 2000;**42**(12):816-24.
6. Bax M, Flodmark O, Tydeman C. *Definition and classification of cerebral palsy. From syndrome toward disease*. *Dev Med Child Neurol Suppl* 2007;**109**:39-41.
7. Mutch L, Alberman E, Hagberg B, Kodama K, Perat M. *Cerebral palsy epidemiology: where are we now and where are we going?* *Dev Med Child Neurol* 1992;**34**(6):547-51.
8. Stanley F, Blair E, Alberman E. *Epidemiological issues in evaluating the management of cerebral palsy*, in *Cerebral Palsies: Epidemiology and Causal Pathways*. London: MacKeith Press, 2000:176-94.
9. *The Economic Impact of Cerebral Palsy in Australia in 2007*, Cerebral Palsy Australia, Access Economics, 2007
10. *Australian Bureau of Statistics Population Clock, December 2009*, Australian Bureau of Statistics, 2009
11. Badawi N, Watson L, Petterson B, Blair E, Slee J, Haan E, Stanley F. *What constitutes cerebral palsy?* *Dev Med Child Neurol* 1998;**40**(8):520-7.
12. National Perinatal Data Development Committee. *Perinatal period 2005*, Australian Institute of Health and Welfare, 2005.
13. Laws P, Sullivan E. *Australia's mothers and babies 2003, Perinatal Statistics Series* Sydney, 2005.
14. Waters A, Dean J, Sullivan E. *Assisted reproduction technology in Australia and New Zealand 2003, Assisted reproduction technology series*, Australian Institute of Health and Welfare, 2006:68
15. SCPE. *Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers*. *Dev Med Child Neurol* 2000;**42**:818-24.

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

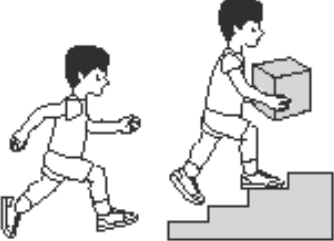
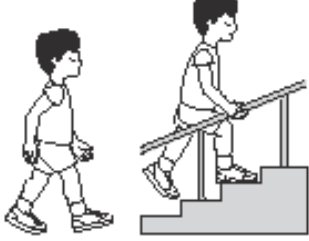
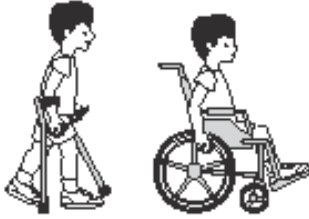
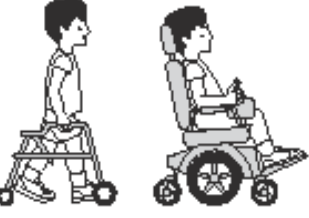

E linda@ichr.uwa.edu.au

T 08 9489 7766

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

| | |
|---|--|
|  | <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> |

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 - REFERENCES GENERATED BY REGISTERS IN AUSTRALIA

- Amor DJ, Craig JE, Delayck MB, Reddihough DS. Genetic factors in athetoid cerebral palsy. *Journal of Child Neurology*. 2001;16:793-797.
- Atkinson S, Stanley FJ. Spastic diplegia in children of low and normal birthweight. *Developmental Medicine and Child Neurology* 1983; 25: 693-708.
- Badawi N, Watson L, Lake B, Alessandri L. Intellectual disability and cerebral palsy. In Banerjee SR (ed), *Community and Social Pediatrics*. New Delhi: Jaypee Brothers Medical Publishers, 1995: 1-13.
- Badawi N, Watson L, Petterson B, Blair E, Slee J, Haan E, Stanley F. What constitutes cerebral palsy?. *Developmental Medicine and Child Neurology*. 1998; 40(8):520-7
- Badawi N. The international consensus statement on cerebral palsy causation. *Medical Journal of Australia*. 2000; 172(5):199-200
- Badawi N, Keogh J, Dixon G, Kurinczuk J. Developmental outcomes of newborn encephalopathy in the term infant. *Indian Journal of Pediatrics*. 2001; 68(6):527-30
- Badawi N, Felix J, Kurinczuk J, Dixon G, Watson L, Keogh J, Valentine J, Stanley F. Cerebral palsy following term newborn encephalopathy: a population-based study. *Developmental Medicine & Child Neurology*. 2005; 47(5):293-8
- Badawi N, Dixon G, Felix J, Keogh J, Petterson B, Stanley F, Kurinczuk J. Autism following a history of newborn encephalopathy: more than a coincidence? *Developmental Medicine & Child Neurology*. 2006; 48(2):85-9
- Badawi N, Novak I, McIntyre S, Edwards K, Raye S, deLacy M, Bevis E, Flett P, van Essen P, Scott H, Tungaraza K, Sealy M, McCann V, Reddihough D, Reid S, Lanigan A, Blair E, de Groot J, Watson L. Proposed new definition of cerebral palsy does not solve any of the problems of existing definitions. Letter to the Editor. *Developmental Medicine and Child Neurology* 2006;48:78-80.
- Baikie G, South MJ, Reddihough DS, Cook DJ, Cameron DJS, Olinsky A, Ferguson E. B. Agreement between tests of aspiration in children with severe cerebral palsy using barium video-fluoroscopy, milk scan and salivagram. *Developmental Medicine and Child Neurology*. 2005;47:86-93.
- Blair E, Stanley FJ. An epidemiological study of cerebral palsy in Western Australia, 1956-1975. III: Cerebral palsy of postnatal aetiology. *Developmental Medicine and Child Neurology* 1982; 24: 575-585.
- Blair E, Stanley FJ. Interobserver agreement in the classification of cerebral palsy. *Developmental Medicine and Child Neurology* 1985; 27: 615-622.
- Blair EM, Stanley FJ. Intrapartum asphyxia: A rare cause of cerebral palsy. *Journal of Pediatrics* 1988; 112: 515-519.
- Blair EM, Stanley FJ. Intrauterine growth and spastic cerebral palsy. I: The association of birthweight for gestational age. *American Journal of Obstetrics and Gynecology* 1990; 162: 229-237
- Blair E, Stanley FJ, Hockey A. Intrapartum asphyxia and cerebral palsy [letter]. *Journal of Pediatrics* 1992; 121: 170-171.
- Blair EM, Stanley FJ. Intrauterine growth and spastic cerebral palsy. II: The association with morphology at birth. *Early Human Development* 1992; 28: 91-103.
- Blair E, Stanley FJ. When can spastic cerebral palsy be prevented? The generation of causal hypotheses by multivariate analysis of a case-control study. *Paediatric and Perinatal Epidemiology* 1993; 7: 272-301.
- Blair E, Stanley FJ. Aetiological pathways to spastic cerebral palsy. *Paediatric and Perinatal Epidemiology* 1993; 7: 302-317.
- Blair E, Palmer L, Stanley FJ. Cerebral palsy in very low birthweight infants, pre-eclampsia and magnesium sulphate [letter]. *Pediatrics* 1996; 97: 780-781.
- Blair E, Shean R. Trends in childhood disability. *Med.J.Aust.* 1996;165:206-208.
- Blair E. Obstetric antecedents of cerebral palsy. *Fetal and Maternal Medicine Review* 1996; 8: 199-215.
- Blair E, Stanley FJ. Issues in the classification and epidemiology of cerebral palsy [invited review]. *Mental Retardation and Developmental Disabilities Research Reviews* 1997; 3: 184-193.
- Blair E. Paediatric implications of intrauterine growth restriction with special reference to cerebral palsy. In P Baker, J Kingdom (eds), *Intrauterine Growth Restriction*. London: Springer-Verlag, 2000.
- Blair E, Wallman A. Changing rates of severity of cerebral palsy and implications for practice. *Action Packed* 2000, 5(3): 18-20.
- Blair E. Trends in cerebral palsy. *Indian Journal of Paediatrics* 2001; 68: 433-438.
- Blair E, Watson L, Badawi N, Stanley FJ. Life expectancy among people with cerebral palsy in Western Australia. *Developmental Medicine and Child Neurology* 2001; 43: 508-515.
- Blair E, Stanley F. The epidemiology of the cerebral palsies. In Levene MI, Cherenak FA, Whittle M (eds), *Fetal and Neonatal Neurology and Neurosurgery, Third Edition*. London: Churchill Livingstone, 2001: 791-798.
- Blair E, Stanley F. Causal pathways to cerebral palsy. *Current Paediatrics* 2002; 12(3): 179-185.
- Blair E, Stanley F. New thoughts on the aetiology of cerebral palsy. In Sturdee D, Olah K, Purdie D, Keane D (eds), *The Yearbook of Obstetrics and Gynecology, Volume 10*. London: RCOG Press, 2002: 357-367.
- Blair E, Watson L. Epidemiology of cerebral palsy. In Doyle L (ed), *Perinatal and Neonatal Epidemiology, Seminars in Fetal and Neonatal Medicine* 2006; 11: 117-1125

- Blair E, Bower C, Badawi N, Al Asedy F. 2007 Are non-cerebral birth defects associated with cerebral palsy? *Developmental Medicine and Child Neurology* 2007;49(4):252-258.
- Bryce RL, Stanley FJ, Blair EM. The effects of intrapartum care on handicap. In M Enkin, M Keirse, I Chalmers (eds), *Effective Care in Pregnancy and Childbirth*. Oxford: OUP, 1988.
- Camfield CS, Camfield P, Watson L. Cerebral palsy in children with epilepsy. In Devinsky O, Westbrook LE (eds), *Epilepsy and Developmental Disabilities*. Boston: Butterworth-Heinemann, 2002.
- Catanese A., Coleman GJ, King JA, Reddihough DS. Evaluation of an early childhood programme based on principles of Conductive Education: The Yooralla Project. *Journal of Paediatrics and Child Health* 1995;31:418-422.
- Cathels BA, Reddihough DS. The health care of young adults with cerebral palsy. *Medical Journal of Australia*. 1993;159:444-446.
- Dale A, Stanley FJ. An epidemiological study of cerebral palsy in Western Australia, 1956-1975. II: Spastic cerebral palsy and perinatal factors. *Developmental Medicine and Child Neurology* 1980; 22: 13-25
- Davis, E., Waters, E., Mackinnon, A., Reddihough, D., Graham, H.K., Mehmet-Radji, O., & Boyd, R. Paediatric quality of life instruments: a review of the impact of the conceptual framework on outcomes. *Developmental Medicine and Child Neurology* 2006;48:311-318
- Davis E, Shelly A, Waters E, Boyd R, Cook K, Casey E, Reddihough D. The impact of caring for a child with cerebral palsy: Quality of life for mothers and fathers. Accepted for publication in *Child: Care, Health and Development*, January 2008.
- Davis E, Shelly A, Waters E, Boyd R, Cook K, Casey E, Reddihough D. The impact of caring for a child with cerebral palsy: Quality of life for mothers and fathers. Accepted for publication in *Child: Care, Health and Development*, January 2008.
- Davis E, Shelly A, Waters E, Mackinnon A, Reddihough D, Boyd R, Graham HK. Quality of life for adolescents with cerebral palsy: Perspectives of adolescents and parents. *Developmental Medicine and Child Neurology*, Accepted for publication January 2008.
- Dite GS, Reddihough DS, Robert LA (1994) Report of the Victorian Cerebral Palsy Register. Royal Children's Hospital, Melbourne.
- Dite GS, Reddihough DS, Robert LA (1995) Second Report of the Victorian Cerebral Palsy Register. Royal Children's Hospital, Melbourne.
- Dite GS, Bell R, Reddihough DS, Bessell C, Brennecke S, Sheedy M. Antenatal and perinatal antecedents of moderate and severe spastic cerebral palsy. *Australian and New Zealand Journal of Obstetrics and Gynaecology*. 1998;38:1-7.
- Dite GS, Reddihough DS, Robert LA (2005) Second Report of the Victorian Cerebral Palsy Register. Royal Children's Hospital, Melbourne.
- Dixon G, Badawi N, Kurinczuk J, Keogh J, Silburn S, Zubrick S, Stanley, F. Early developmental outcomes after newborn encephalopathy. *Pediatrics*. 2002; 109(1):26-33
- Djukic M, Gibson CS, MacLennan AH, Goldwater PN, Haan EA, McMichael GL, Priest K, Dekker GA, Hague, WM, Chan A, Rudzki Z, van Essen PB, Khong TY, Morton MR, Ranieri E, Scott H, Tapp H, Casey G. Genetic susceptibility to viral exposure may increase the risk of cerebral palsy. *Australian and New Zealand Journal of Obstetrics and Gynaecology* 2009; 49: 247-253.
- Gibson CS, MacLennan AH, Goldwater PN, Dekker GA. Antenatal causes of cerebral palsy: associations between inherited thrombophilias, viral and bacterial infection, and inherited susceptibility to infection. *Obstet Gynecol Surv* 2003; 58:209-20.
- Gibson CS, MacLennan AH, Rudzki Z, Hague WM, Haan EA, Sharpe P, Priest K, Chan A, Dekker GA for the South Australian Cerebral Palsy Research Group. The prevalence of inherited thrombophilias in a Caucasian Australian population. *Pathology* 2005; 37:160-163.
- Gibson CS, MacLennan AH, Hague WM, Haan EA, Priest K, Chan A, Dekker GA for the South Australian Cerebral Palsy Research Group. Associations between inherited thrombophilias, gestational age, and cerebral palsy. *Am J Obstet Gynecol* 2005; 193:1437.
- Gibson CS, MacLennan AH, Janssen NG, Kist WJ, Hague WM, Haan EA, Goldwater PN, Priest K, Dekker GA for the South Australian Cerebral Palsy Research Group. Associations between fetal inherited thrombophilia and adverse pregnancy outcomes. *Am J Obstet Gynecol* 2006; 194: 947.e1-947.e10.
- Gibson CS, MacLennan AH, Goldwater PN, Haan EA, Priest K, Dekker GA for the South Australian Cerebral Palsy Research Group. Neurotropic viruses and cerebral palsy: population based case-control study. *BMJ* 2006; 332(7533):76-80.
- Gibson CS, MacLennan AH, Goldwater PN, Haan EA, Priest K, Dekker GA for the South Australian Cerebral Palsy Research Group. The association between inherited cytokine polymorphisms and cerebral palsy. *Am J Obstet Gynecol* 2006; 194:674 e1-11.
- Gibson CS, MacLennan AH, Dekker GA, Goldwater PN, Dambrosia JM, Munroe DJ, Tsang S, Stewart C, Nelson KB. Genetic polymorphisms and spontaneous preterm birth. *Obstet Gynecol* 2007; 109 (2 pt 1): 384-391.
- Gibson CS, MacLennan AH, Dekker GA, Goldwater PN, Sullivan TR, Munroe DJ, Tsang S, Stewart C, Nelson KB. Candidate genes and cerebral palsy: a population-based study. *Pediatrics* 2008; 122: 1079-1085.
- Gibson CS, MacLennan AH, Goldwater PN, Dekker GA. The antenatal origins of cerebral palsy – genetic and viral associations. *Fetal and Maternal Medicine Review* 2008; 19: 181-201.
- Gibson CS, MacLennan AH, Goldwater PN, Haan EA, Priest K, Dekker GA. Mannose-binding lectin haplotypes may be associated with cerebral palsy only after perinatal viral exposure. *Am J Obstet Gynecol* 2008; 198: 509e1-509e8.
- Gibson CS, Goldwater PN, MacLennan AH, Haan EA, Priest K, Dekker GA. Fetal exposure to herpesviruses may be associated with pregnancy-induced hypertensive disorders and preterm birth in a Caucasian population. *BJOG* 2008; 115: 492-500.
- Gilles MT, Blair E, Watson L, Badawi N, Alessandri L, Dawes V, Plant AJ, Stanley FJ. Trauma in pregnancy and cerebral palsy: Is there a link? *Med J Aust* 1996; 164: 500-501.
- Hallett KB, Lucas JO, Johnston T, Reddihough DS, Hall R. Dental health of children with cerebral palsy following sialochodochoplasty. *Journal of Special Care in Dentistry*. 1995;15:234-238.
- Halliday JL, Reddihough D, Byron K, Ekert H, Ditchfield M. Hemiplegic cerebral palsy and the factor V Leiden mutation (Letter to the Editor). *Journal of Medical Genetics*. 2000;37:787-789
- Howard J, Soo B, Graham H K, Boyd R, Reid S, Lanigan A, Wolfe R, Reddihough. Cerebral Palsy in Victoria: Motor Types, Topography and Gross Motor Function. Accepted for publication in the *Journal of Paediatrics and Child Health*, February 2005.

- Imms C, Reilly S, Carlin J, Dodd K. Diversity of participation in children with cerebral palsy. *Dev Med Child Neurol* 2008; 50: 363-9.
- Jongeling B, Badawi N, Kurinczuk J, Thonell S, Watson L, Dixon G, Stanley F. Cranial ultrasound as a predictor of outcome in term newborn encephalopathy. *Pediatric Neurology*. 2002; 26(1):37-42
- Lawson RD, Badawi N. Etiology of cerebral palsy. *Hand Clinics*. 2003; 19(4):547-56
- McMichael GL, Gibson CS, Goldwater PN, Haan EA, Priest K, Dekker GA, MacLennan AH. Association between Apolipoprotein E genotype and cerebral palsy is not confirmed in a Caucasian population. *Human Genetics* 2008; 124: 411-416.
- Palmer L, Petterson B, Blair E, Burton P. Family patterns of gestational age at delivery and growth in utero in moderate and severe cerebral palsy. *Developmental Medicine and Child Neurology* 1994; 36: 1108-1119.
- Palmer L, Petterson B, Blair E, Burton P. Antenatal antecedents of moderate and severe cerebral palsy. *Paediatric and Perinatal Epidemiology* 1995; 9: 171-184.
- Peek A, van Essen P, Gibson CS, Scott H, Chan A, Haan E. 2007 Annual Report of The South Australian Cerebral Palsy Register. Adelaide: South Australian Cerebral Palsy Register, Children, Youth and Women's Health Service, 2008.
- Petterson B, Stanley FJ, Henderson D. Cerebral palsy in multiple births in Western Australia, 1956-80. *American Journal of Medical Genetics* 1990; 37: 346-351.
- Petterson B, Stanley FJ. Spastic quadriplegia in Western Australia: A genetic epidemiological study. II. Pedigrees and family patterns of birth weight and gestational age. *Developmental Medicine and Child Neurology* 1993; 35: 202-215.
- Petterson B, Nelson KB, Watson L, Stanley FJ. Twins, triplets and cerebral palsy in births in Western Australia in the 1980s. *British Medical Journal* 1993; 307: 1239-1243.
- Petterson B, Blair E, Watson L, Stanley F. Adverse outcome after multiple pregnancy. *Bailliere's Clinical Obstetrics and Gynaecology* 1998; 12: 1-17.
- Reddihough DS, Baikie G, Walstab J. Cerebral palsy in Victoria: mortality and causes of death. *Journal of Paediatrics and Child Health*. 2001; 37:183-186.
- Reddihough DS, Collins KJ. The epidemiology and causes of cerebral palsy. *Australian Journal of Physiotherapy*. 2003;49:7-12.
- Reid SM, Lanigan A, Walstab JE, Reddihough DS. The Victorian Cerebral Palsy Register: Third Report 2005. Murdoch Childrens Research Institute, Melbourne.
- Reid SM, Lanigan A, Reddihough D Postneonataly-acquired cerebral palsy in Victoria, Australia, 1970-1999. Accepted for publication in the *Journal of Paediatrics and Child Health*. March 2006
- Reid S, Halliday J, Ditchfield M, Ekert H, Byron K, Glynn A, Petrou V, Reddihough, D. Factor V Leiden mutation – a contributory factor for cerebral palsy? *Developmental Medicine and Child Neurology*, 2006; 48:14-19.
- Rice J, Russo R, Halbert J, van Essen P, Haan E. Motor function in five-year-old children with cerebral palsy in the South Australian population. *Dev Med Child Neurol* 2009; 57(7): 551-556.
- Robinson M, Peake L, Ditchfield M, Reid S, Lanigan A, Reddihough D. Magnetic resonance imaging findings in a population-based cohort of children with cerebral palsy. Accepted for publication in *Developmental Medicine & Child Neurology*, April 2008
- Russo RN, Crotty M, Miller MD, Murchland S, Flett P, Haan E. Upper limb botulinum toxin A injection and occupational therapy in children with hemiplegic cerebral palsy identified from a population register: a single blind randomised controlled trial. *Pediatrics* 2007; 119(5): e1149-58.
- Scher AI, Petterson B, Blair E, Ellenberg JH, Grether JK, Haan E, Reddihough DS, Yeargin-Allsopp M, Nelson KB. The risk of mortality or cerebral palsy in twin: a collaborative population-based study. *Pediatric Research*,2002;52:671-681
- Scott H, Tungaraza K, van Essen P, Chan A, Haan E. 2003 Annual Report of The South Australian Cerebral Palsy Register. Adelaide: South Australian Cerebral Palsy Register, Women's and Children's Hospital, 2004.
- Scott H, Davies AM, van Essen P, Chan A, Haan E. 2005 Annual Report of The South Australian Cerebral Palsy Register. Adelaide: South Australian Cerebral Palsy Register, Children, Youth and Women's Health Service, 2006.
- Sharpe P, Gilbert M, Scott H, Chan A, Haan E. 2001 Annual Report of The South Australian Cerebral Palsy Register. Adelaide: South Australian Cerebral Palsy Register, Women's and Children's Hospital, 2002.
- Sharpe P, Tungaraza K, Scott H, Chan A, Haan E. 2002 Annual Report of The South Australian Cerebral Palsy Register. Adelaide: South Australian Cerebral Palsy Register, Women's and Children's Hospital, 2003.
- Shelly A, Davis E, Waters E, Mackinnon A, Reddihough D, Boyd R, Reid S, Graham HK. The relationship between quality of life (QOL) and functioning for children with cerebral palsy. *Developmental Medicine and Child Neurology* 2008;50:199-203.
- Skok A, Harvey D, Reddihough D. Perceived stress, perceived social support, and wellbeing among mothers of school-aged children with cerebral palsy: a brief report. *Journal of Intellectual & Developmental Disability*. 2006;31(1):53-57.
- Soo B, Howard J, Boyd R, Reid S, Lanigan A, Wolfe R, Reddihough D, Graham H K Hip displacement in cerebral palsy: Hip displacement in cerebral palsy. *Journal of Bone and Joint Surgery* 2006; 88:121-129.
- Stanley FJ. An epidemiological study of cerebral palsy in Western Australia, 1956-1975. I: Changes in total incidence of cerebral palsy and associated factors. *Developmental Medicine and Child Neurology* 1979; 21: 701-713.
- Stanley FJ. Neonatal mortality and cerebral palsy: The impact of neonatal intensive care. *Australian Paediatric Journal* 1980; 16: 35-39.
- Stanley FJ. The epidemiology of cerebral palsy. In Araujo L (ed), *Cerebral Palsy*. Rio de Janeiro: Livra Editora S.A.
- Stanley FJ. Spastic cerebral palsy: Changes in birthweight and gestational age. *Early Human Development* 1981; 5: 167-178.
- Stanley FJ. The use of a register in assessing the level of handicap in the community: The WA Cerebral Palsy Register. *Community Health Studies* 1982; 6: 135-143.

- Stanley FJ, Watson L, Mauger S. The First Report of the Western Australian Cerebral Palsy Register. Perth: NHMRC Research Unit in Epidemiology and Preventive Medicine, 1984.
- Stanley FJ, Watson LD. Methodology of a cerebral palsy register: The Western Australian experience. *Neuroepidemiology* 1985; 4: 146.
- Stanley FJ, English DR. Prevalence of and risk factors for cerebral palsy in a total population cohort of low birthweight (<2000g) infants. *Developmental Medicine and Child Neurology* 1986; 28: 559.
- Stanley FJ, Watson L, Mauger S. The Second Report of the Western Australian Cerebral Palsy Register. Perth: NHMRC Research Unit in Epidemiology and Preventive Medicine, 1987.
- Stanley FJ. The changing face of cerebral palsy. *Developmental Medicine and Child Neurology* 1987; 29: 258-270.
- Stanley FJ, Watson LD. The cerebral palsies in Western Australia: Trends, 1968 to 1981. *American Journal of Obstetrics and Gynecology* 1988; 158: 89-93.
- Stanley FJ, Blair E. Why have we failed to reduce the frequency of cerebral palsy? *Medical Journal of Australia* 1991; 154: 623-626.
- Stanley FJ, Watson LW. Trends in perinatal mortality and cerebral palsy in Western Australia. *British Medical Journal* 1992; 304: 1658-1663.
- Stanley FJ. Trends in cerebral palsy in Western Australia [letter]. *British Medical Journal* 1992; 305: 525-526.
- Stanley FJ, Blair E. Cerebral palsy and the quality of obstetric care. *Cerebral Palsy Today* 1992; 1(4): 1-3.
- Stanley FJ. Survival and cerebral palsy in low birth weight infants: implications for perinatal care. *Paediatric and Perinatal Epidemiology* 1992; 6: 298-310.
- Stanley FJ, Blair E, Petterson B, Hockey A, Watson L. Spastic quadriplegia in Western Australia: A genetic epidemiological study. I. The case population and perinatal risk factors. *Developmental Medicine and Child Neurology* 1993; 35: 191-201.
- Stanley FJ, Blair E. Cerebral palsy. In: Pless IB (ed), *The Epidemiology of Childhood Disorders*. New York: Oxford University Press, 1994.
- Stanley FJ. The aetiology of cerebral palsy. *Early Human Development* 1994; 36: 81-88.
- Stanley FJ. Cerebral palsy trends. Implications for perinatal care. *Acta Obstetrica et Gynecologica Scandinavica* 1994; 73: 5-9.
- Stanley FJ. Obstetrical responsibility for abnormal fetal outcome. In Chamberlain G (ed), *Turnbull's Obstetrics*, 2nd Edition. London: Churchill Livingstone, 1995: 833-844.
- Stanley FJ, Petterson B. Cerebral palsy in multiple births: the changing epidemiological patterns. In Ward RH and Whittle M (eds), *Multiple Pregnancy*. London: RCOG Press, 1995: 309-325.
- Stanley FJ, Blair E, Westaway J. Cerebral palsy. The role of obstetric care in pregnancy and delivery. A monograph for lawyers, parents and doctors. Perth: United Medical Defence, 1995.
- Stanley FJ. Prenatal determinants of motor disorders. *Acta Paediatr Suppl* 1997; 422: 92-102
- Stanley FJ, Alberman ED, Blair E. *The Cerebral Palsies: Epidemiology and Causal Pathways*. Spastics International Medical Publications, Clinics in Developmental Medicine. London: Blackwells, 2000.
- Strijbis EMM, Oudman I, van Essen P, MacLennan AH. Cerebral palsy and the application of the international criteria for acute intrapartum hypoxia. *Obstet Gynecol* 2006; 107:1357.
- van Essen P, Tungaraza K, Scott H, Chan A, Haan E. 2004 Annual Report of The South Australian Cerebral Palsy Register. Adelaide: South Australian Cerebral Palsy Register, Children, Youth and Women's Health Service, 2005.
- van Essen P, Peek A, Scott H, Chan A, Haan E. 2006 Annual Report of The South Australian Cerebral Palsy Register. Adelaide: South Australian Cerebral Palsy Register, Children, Youth and Women's Health Service, 2007.
- Walstab J, Bell R, Reddihough D, Brennecke S, Bessel C, Beischer N. Antenatal and intrapartum antecedents of cerebral palsy – a case-control study. *Aust NZ J Obstet Gynaecol* 2002;42:2:138-146.
- Walstab J, Bell R, Reddihough D, Brennecke S, Bessel C, Beischer N. Maternal antecedents to cerebral palsy in preterm infants. Letter to the Editor. *Developmental Medicine and Child Neurology*. 2002;44:498.
- Walstab JE, Bell RJ, Reddihough DS, Brennecke SP, Bessel CK and Beischer NA. Factors identified during the neonatal period associated with the risk of cerebral palsy. *Australian and New Zealand Journal of Obstetrics and Gynaecology* 44: 342-346 (2004)
- Waters E, Davis E, Reddihough D, Graham HK, Mackinnon, A, Wolfe, R, Stevenson, R, Bjornsen, K, Blair, E, Hoare, P, Ravens-Sieberer, U, Boyd, R. A new condition-specific quality of life scale for children with cerebral palsy. *PRO Newsletter*, 2005; 35: 10-12.
- Waters E, Maher E, Salmon L, Reddihough D, Boyd R. Development of a condition-specific measure of quality of life for children with cerebral palsy: empirical thematic data reported by parents and children. *Child: Care, Health and Development* 2005;31(2):127-135
- Waters, E, Davis E, Mackinnon A, Boyd R, Graham H, Lo S, Wolfe R, Stevenson R, Bjornson K, Blair E, Hoare P, RavensSieberer U. Reddihough D, *Cerebral Palsy Quality of Life Questionnaire for Children (CP QOL- Child): Psychometric properties of the quality of life questionnaire for children with CP*. *Developmental Medicine and Child Neurology*. 2007;49:-55.
- Watson L, Stanley F, Blair E. Report of the Western Australian Cerebral Palsy Register to Birth Year 1994. Perth: TVW Telethon Institute for Child Health Research, Dec 1999.
- Watson L, Stanley F, Blair E. Report of the Western Australian Cerebral Palsy Register to Birth Year 1999. Perth: TICHR, 2006.
- Yin R, Reddihough DS, Ditchfield MR, Collins KJ. MRI findings in cerebral palsy. *Journal of Paediatrics and Child Health* 2000;36:139-144

Contact Details

T 02 8204 4495

E cprester@tscnsw.org.au

W <https://secure.cprester-aus.com.au>



Piecing together the facts on cerebral palsy