

**2006 Annual Report**  
**of**  
**The South Australian Cerebral Palsy Register**  
*(part of The South Australian Birth Defects Register)*

**Children born 1993 to 2001 with cerebral palsy  
notified to the Register by 31<sup>st</sup> December 2006**

**August 2007**

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## The South Australian Cerebral Palsy Register

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### Register Staff

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A/Professor Annabelle Chan	<i>Public Health Physician</i>
Ms Phillipa van Essen	<i>Manager, SA Birth Defects Register</i>
Ms Ann Peek	<i>Register Officer, Cerebral Palsy Register</i>

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Dr Andrew Tidemann	<i>Paediatric Rehabilitation Specialist</i>
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A/Professor Annabelle Chan	<i>Representing SA Department of Health, Epidemiology Branch</i>
Dr Ray Russo	<i>Paediatric Rehabilitation Specialist</i>
Ms Phillipa van Essen	<i>Manager, SA Birth Defects Register</i>
Ms Ann Peek	<i>Register Officer, Cerebral Palsy Register</i>

### Collaborating Organisations

Novita Children's Services  
Flinders Medical Centre  
Children, Youth and Women's Health Service

### Funding

The Register is funded by the Children, Youth and Women's Health Service, with additional support provided by Novita Children's Services of South Australia and the Community Accommodation and Respite Agency (CARA).

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## The South Australian Cerebral Palsy Register – Annual Report 2006

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## Foreword

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As a co-founder of the South Australian Cerebral Palsy Register in the 1990's, it is with great pleasure that I write this foreword to the Annual Report. While valuable data has been gathered for diverse research purposes, what has changed recently as far as a register of this kind is concerned?

Firstly, we know that cerebral palsy is the most common physical disability in children. There are at least 600 new cases of cerebral palsy in Australia every year and approximately 40 of those are from South Australia.

Secondly, revisiting the definition and classification (or perhaps better still the description) of cerebral palsy has been occurring in earnest this decade. No-one has proposed changing the term 'Cerebral Palsy' itself, but its definition and description has been subject to renewed international discussion and debate again recently. Some of the subcategory terms such as 'diplegia' and 'hemiplegia' have already been replaced in some parts of the World by terms like 'bilateral' and 'unilateral' CP respectively.

The search for a better and more contemporary definition of cerebral palsy, recognising potential functional and health problems beyond the essential motor disability, started in earnest again around 2003-4. After vigorous international debate in 2004, a new definition modified after Bax et al 2005<sup>1</sup> became: "*Cerebral palsy describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disturbances are often accompanied by disturbances of sensation, perception, cognition, communication, behaviour, by epilepsy and by secondary musculoskeletal problems.*" Concerns have been expressed since about the second 'linking' sentence however and the possibility of broadening the definition too far to include children who have not traditionally been regarded as having CP, and in particular clumsy children with Developmental Coordination Disorder (DCD). Earlier this year, in the prestigious journal *Developmental Medicine and Child Neurology*, changes have already been proposed to that sentence to read "A full description of the individual with CP requires classification of the motor abnormalities, associated impairments, anatomic findings, and definition of function according to the World Health Organisation (WHO) International Classification of Function" (Armstrong 2007)<sup>2</sup>. Moreover, the writer urged that his altered second sentence be regarded as a 'linking' sentence, and not essential to the basic definition of CP.

Even though we have known for a long time that the term 'cerebral palsy' cannot be equated with function or severity of disability, the core elements of the diagnosis as far as families are concerned are likely to remain as before: namely, that CP is an umbrella term to describe a range of disorders; that CP is permanent but not unchanging with or due to growth and development; that CP is a disorder of movement and posture and of motor function; and that CP is due to a non-progressive interference, lesion or abnormality in the immature brain.

Beyond the above modifications to definition, why is this so important for cerebral palsy registers? It is becoming more apparent to clinicians involved that with new knowledge and evaluation tools we also have more opportunities to robustly assess and then accurately and consistently record clinical data in a standardised protocol. The national CP register groups, led especially by WA, have been making important progress towards a method of quantifying spasticity for example and of recording clinical findings in a simple format for subsequent research. Contributing to a national database of children with CP will ultimately provide larger numbers for research purposes of many kinds, not just into causal pathways and the monitoring of trends across Australia as important as they are, but also for service planning purposes and for collaborative clinical trials to determine more effective interventions and supports for those with CP.

The SA Register has been the only register in Australia up to now that has involved the undertaking of a medical examination at 5 years of age for the purposes of confirming diagnosis, of recording traditional categories of CP, and of recording associated health and developmental issues at the point of entry into school. It has been a good example of quiet leadership.

May I extend my congratulations and best wishes to the SA Cerebral Palsy Register team for their ongoing endeavours within South Australia and also nationally.



Dr Peter Flett  
Statewide Director, Paediatric Rehabilitation  
Paediatric Rehabilitation Specialist  
Calvary Health Care, Tasmania



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## South Australian Cerebral Palsy Register Staff

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### South Australian Cerebral Palsy Register Staff

**Left to Right:** Ms Ann Peek, A/Professor Annabelle Chan, Professor Eric Haan and Ms Phillipa van Essen

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## Summary

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The South Australian Cerebral Palsy Register is a population-based collection of information on children with cerebral palsy born in South Australia in a population with an average of 18,763 live births per year (1993-2001).

This report presents information for children with cerebral palsy born in the years 1993-2001.

The term cerebral palsy describes a group of permanent and non-progressive disorders of movement and posture that manifest early in life and result from a defect or lesion of the immature brain. Individuals with cerebral palsy have life-long motor disabilities, frequently associated with intellectual disability, epilepsy and visual and hearing impairment. It is the most common chronic motor disability of childhood and places a large emotional and financial burden on those affected and their families.

The types of cerebral palsy are based on clinical features and comprise of spastic quadriplegia, spastic triplegia, spastic diplegia, spastic hemiplegia, monoplegia, ataxia and dyskinesia.

Children with cerebral palsy are ascertained through notifications to the South Australian Birth Defects Register from Novita Children's Services, rehabilitation specialists, other paediatricians and the Neonatal Long Term Follow-up Programs of Flinders Medical Centre and Children, Youth and Women's Health Service.

At around five years of age, a comprehensive medical history is obtained and the children have a formal clinical assessment to ensure that the diagnosis of cerebral palsy is correct, to document the type and severity of the disorder, and to define the disabilities experienced by the child.

Parental consent is obtained for children to participate in the clinical assessment at 5 years of age.

For the years 1993-2001, 356 children with cerebral palsy were ascertained. At 31<sup>st</sup> December 2006, 71% of these children had had their comprehensive clinical assessment, at around five years of age.

The maximum and minimum prevalence rate of cerebral palsy between 1993-2001, per 1,000 live births, is presented. The minimum rate represents the cases confirmed by examination at five years, and the maximum rate reflects the total ascertained cases. Between 1993-2001 the minimum rate of cerebral palsy was 1.49 per 1,000 live births, and the maximum rate of cerebral palsy was 2.11 per 1,000 live births.

Paediatric rehabilitation specialists notified 44% of cases, Novita Children's Services 25%, the South Australian Birth Defects Register 23%, other specialists 4%, and other sources 5%.

Hemiplegia (34%) and diplegia (34%) were the most common forms of cerebral palsy, followed by quadriplegia (21%), triplegia (4%) and ataxia (3%). dyskinetic athetoid (2%), monoplegia, hypotonia and dyskinetic dystonic (<1%) were less common forms of the disorder. In 2% of cases, the type of cerebral palsy was unknown.

51.9% of affected children were born prematurely (<37 weeks), 48.1% were born at term (≥37 weeks).

The association between the risk of cerebral palsy and prematurity is exemplified by a prevalence of 88.4 cases per 1,000 live births at 23-27 weeks gestation compared to 1.9 cases per 1,000 live births at term (≥37 weeks).

51.1% of affected children had a birth weight ≥2,500 grams, 18.8% weighed 1,500-2,499 grams, 13.5% weighed 1,000-1,499 grams, and 16.6% weighed <1,000 grams.

The prevalence of cerebral palsy was 80.7 cases per 1,000 among live births with birth weights in the 500-999 g range, but only 0.8 per 1,000 among live births with a birth weight in the 3,500-3,999 g range.

69% of affected children had relatively mild cerebral palsy (gross motor function Levels I and II) while 30% had more severely affected gross motor function (Levels III-V) and 1% of cases had an unknown level of motor function.

32% of children with cerebral palsy born between 1993 and 2001 had impaired intellectual ability, 38% had impaired vision and 13% had impaired hearing.

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## Thanks to Notifiers / Acknowledgments

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We wish to thank all notifiers to the register, including paediatricians, staff of Novita Children's Services of South Australia and the families of children with cerebral palsy. In particular we would like to thank the staff of the Department of Child and Adolescent Development, Neurology and Rehabilitation of the Children, Youth and Women's Health Service.

We would especially like to thank and acknowledge the Rehabilitation Specialists and paediatricians who complete the Data Collection Form. Dr Ray Russo, Dr Andrew Tidemann, Dr Deidre White, Dr Peter Flett, Dr Kathy Lee and Dr Phil Egan.

We acknowledge the ongoing assistance of the staff of the Department of Medical Records at Flinders Medical Centre, The Queen Elizabeth Hospital, Lyell McEwin Health Service and Children, Youth and Women's Health Service. Special thanks must also go to staff of the Pregnancy Outcome Statistics Unit of the Epidemiology Branch, Department of Health for their invaluable assistance.

### **Acknowledgments**

The Register gratefully acknowledges funding from the Community Accommodation and Respite Agency (CARA), which allowed the Register to upgrade its computing in 2004.

We would like to thank all those people and organisations who have contributed to the South Australian Cerebral Palsy Register during its planning stage and since its inception; their ongoing support and practical contribution is much appreciated.

Special thanks are due to:

- Novita Children's Services, formerly Crippled Children's Association of South Australia (CCA)
- The Community Accommodation and Respite Agency (CARA)
- Paediatricians from specialist centres and in private practice
- Staff of the Department of Child and Adolescent Development, Neurology and Rehabilitation of the Children, Youth and Women's Health Service
- Long Term Follow-Up Program coordinators from the Children, Youth and Women's Health Service and Flinders Medical Centre
- Staff of the South Australian Clinical Genetics Service, Children, Youth and Women's Health Service.

While there are many who have contributed to the Cerebral Palsy Register, there would be no Register without the kind cooperation of the families of affected children. These families live with the effects of cerebral palsy on a daily basis. Once again the Register owes them a debt of gratitude for allowing us to enter their lives and for their insightful comments over the year.



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## What is Cerebral Palsy?

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Cerebral palsy is a term of convenience applied to a group of motor disorders of central origin defined by a clinical description (Badawi et al, 1999) <sup>3</sup>. It covers a range of cerebral disorders that result in childhood motor impairment. The impairment must stem from non-progressive malfunction of the brain (rather than the spinal cord or muscles).

Cerebral palsy affects an individual's ability to control movement and posture. Palsy is an expression used to describe paralysis. A more accurate description of the muscle symptoms might be weakness (paresis) and an inability to make voluntary movements and to suppress involuntary ones.

Unlike many other disorders that affect the motor system, cerebral palsy is not progressive - it does not get worse with time.

In fact, family nurturing, therapy and education can result in improvements in functional outcomes and quality of life.

Approximately 2 in every 1,000 children born in South Australia have cerebral palsy, which equates to approximately 38 newly diagnosed children each year in 1993-2001. The incidence of cerebral palsy has not decreased, despite improvements in ante-, intra- and post-natal care.

Children affected by cerebral palsy will have life-long disabilities and continue to represent a significant proportion of the children and young adults with disabilities in the community. Severity can vary greatly, from minor awkwardness to severe multiple disabilities.

Cerebral palsy can be associated with other disorders, such as epilepsy, learning difficulties, and problems with sight and hearing. There can be difficulties with communication, resulting from multiple disabilities, including problems controlling the speech muscles, intellectual disabilities and poor hearing.

Orthopaedic complications are common, often requiring ongoing care. Most children with cerebral palsy survive to adulthood, although severely affected children may have a reduced life expectancy.

Whilst there is no single cause for cerebral palsy, we do know that there are a number of perinatal factors which are associated, both individually and in combination, with an increased risk of cerebral palsy. These include:

- Prematurity and very low birth weight
- Maternal infections, such as cytomegalovirus (CMV), group B streptococcus and rubella
- Feto-maternal haemorrhage
- Hypoxia during labour and delivery
- The use of certain drugs during pregnancy, such as cocaine
- Excessive alcohol intake during pregnancy
- Metabolic problems in the newborn period, such as severe jaundice and hypoglycaemia.

Recent research using blood specimens from babies obtained soon after birth, has demonstrated an association between evidence of exposure to infection before birth, markers of prenatal inflammation and certain inherited susceptibilities to thrombosis, and the subsequent development of cerebral palsy. (Gibson et al, 2003, Nelson et al, 1998) <sup>4,5</sup>.

There are also events occurring in early childhood (before age 2 years) which may result in "acquired" cerebral palsy. These include:

- Near drowning
- Brain hypoxia from any cause
- Some brain tumours
- Head injuries: accidental and non-accidental
- Severe infection involving the brain, such as meningitis or encephalitis
- Cerebrovascular accidents
- Non accidental injuries
- Complications of inborn errors of metabolism.

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## Funding / Administration / Ethical approval / Legislative framework

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### Funding

The Register is funded by the Children, Youth and Women's Health Service, with additional funding from Novita Children's Services (formerly Crippled Children's Association CCA). Community Accommodation & Respite Agency (CARA) and the Rotary Club of Morialta supported the establishment phase of the Register. The Register gratefully acknowledges funding from the Community Accommodation and Respite Agency (CARA) in 2004 that allowed the Register to upgrade its computing.

### Administration

The Register is based at the Children, Youth and Women's Health Service, and is located administratively within the South Australian Clinical Genetics Service. Its location enables it to draw on the experience and expertise of the Department of Child and Adolescent Development, Neurology and Rehabilitation of the Children, Youth and Women's Health Service. The Specialist Advisers to the Register are drawn from members of these departments and Novita Children's Services.

### Ethical approval

The establishment of the Cerebral Palsy Register was approved by the Human Research Ethics Committees of the Children, Youth and

Women's Health Service, the North Western Adelaide Health Service and Flinders Medical Centre. Continuing ethical oversight of the Register is carried out by the Human Research Ethics Committee of the Children, Youth and Women's Health Service.

### Legislative framework

The Cerebral Palsy Register is part of the SA Birth Defects Register and operates under the provisions of the South Australian Health Commission (Pregnancy Outcome Statistics) Regulations of 1999. This Regulation requires the notification of all congenital abnormalities diagnosed before the child's fifth birthday. Section 64d of the South Australian Health Commission Act, 1976, Amendment Act, 1989 allows the Register to carry out research into cerebral palsy while making provision for maintaining the confidentiality of participants.

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## Aims of the Register

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

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## How the Register Works

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### Ascertainment

Notifications of children with cerebral palsy come from a variety of sources, including Novita Children's Services, paediatricians, physiotherapists, neurologists and occupational therapists. The main sources of notification come from the Children, Youth and Women's Health Service, Novita Children's Services and Paediatric Rehabilitation Specialists. The Register encourages multiple notifications as a means of ensuring complete ascertainment of affected children.

All notifications are received by the SA Birth Defects Register. Once notified, the Register approaches families through a clinician known to them, who will be one of the physicians working with the Register or the child's paediatrician. Information about the Register and its aims is sent to the managing clinician and an invitation to become involved in the Register is extended to the family. The managing clinician is also sent a package containing a family information leaflet and a 'consent to contact' form. Once the clinician has communicated with the family, the package can be forwarded to them. The family can then respond directly to the Register.

The 'consent to contact' form gives the Register permission to contact the family, allowing the Register Officer to give the family detailed information about the Register's aims and functioning. Families are free to refuse participation in the Register. Those who agree to participate may, at any time, ask to be withdrawn from the Register with the knowledge that this will not affect any aspect of the child's medical care. Children included on the Register are given a full clinical assessment at five years of age, performed by a paediatrician working with the Register. By then, it is clear whether or not cerebral palsy is present, and the type and severity can be determined more accurately. Disabilities in addition to the motor disability can also be documented.

The purpose of the assessment is to collect data on the type of cerebral palsy, its severity and any associated disabilities. Information about learning problems, epilepsy, hearing, vision and the use of mobility aids is also collected. A brief family history is obtained to determine if cerebral palsy, intellectual disability or epilepsy has occurred within the immediate or extended family in the past. The method of the child's conception is documented. Information relating to the perinatal period is also collected.

Consents are obtained from families to allow the Register Officer to access information from a variety of sources. The Register works closely with the Pregnancy Outcome Statistics Unit, medical records departments and clinicians in order to ensure accurate and complete data for each child.

### Data Storage

The collected data are stored on computer and are protected by using unique identifier codes to maintain participant confidentiality. All information and participant files are backed up regularly to prevent data loss.

### Confidentiality

The Register does not release identified information about a participant without the written consent of his or her parents or guardian.

### Inclusion and Exclusion Criteria

The Register includes children who have a motor impairment, manifested early in life, which is the result of static cerebral pathology. The Register collects post-neonatally acquired cases of cerebral palsy (after the first month and before age 2 years).

The following disorders are excluded: neurodegenerative conditions, neuromuscular disorders, neural tube defects, tumours, hypotonia occurring in isolation or with intellectual disability, many genetic syndromes and most inborn errors of metabolism. There are many conditions where a decision about inclusion or exclusion can be difficult, and guidance is provided by Badawi et al (1998)<sup>3</sup>.

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## Register activities 2006

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During 2006, Register staff have:

- Refined the data set, database and systems for analysis and interpretation of data
- Participated in the South Australian Cerebral Palsy Research Group, which is investigating whether variations in genes for clotting factors and perinatal infection are associated with cerebral palsy. This has been a highly productive collaboration, with seven articles published in the international peer-reviewed literature in 2005-07.
- Received general queries about setting up a cerebral palsy register from representatives in other Australian States and Territories, and requests for information on consent forms, information pamphlets and legislation.
- Received requests for information from the community and tertiary students who required statistics on the prevalence of cerebral palsy; types of cerebral palsy and associated disabilities in South Australia.
- Received requests for general information about cerebral palsy for Cerebral Palsy Week from the Department of Disabilities Family and Community.
- Collaborated with staff from the Department of Child and Adolescent Development, Neurology and Rehabilitation of the Children, Youth and Women's Health Service as well as staff from the Repatriation General Hospital on a project investigating whether Botox injections can improve upper limb function in children with hemiplegic cerebral palsy.
- Attended the meeting of the Australian Cerebral Palsy Register (ACPR) on 30<sup>th</sup> and 31<sup>st</sup> of October 2006 in Brisbane.
- Attended the meeting of the ACPR State and Territory representatives on Saturday 11 March 2006 to discuss the ACPR website, funding issues and the uploading of test data to the ACPR.
- We would like to say thank you to Ann-Maree Davies who left in 2006, for her contribution to the Register and welcome Ann Peek as the new Register Officer.

## Prevalence of cerebral palsy 1993 - 2001

Tables 1-6 and Figures 1-4 present data about children with cerebral palsy notified to the South Australian Birth Defects Register.

**Table 1**

### SA children with cerebral palsy ascertained by the Register 1993 - 2001

Group	1993	1994	1995	1996	1997	1998	1999	2000	2001	1993-2001	
	No.	No.	No.	No.	No	No	No	No.	No.	No.	(%)
Assessment completed at 5 years	32	32	44	21	42	33	18	21	8	251	(70.5)
Awaiting assessment	-	-	2	2	1	-	3	5	5	18	(5.1)
Consents not completed	1	3	1	1	2	2	2	8	5	25	(7.0)
Medical reports only	4	5	7	4	10	6	8	3	4	51	(14.3)
Deceased prior to 5 years <sup>#</sup>	1	4	-	1	-	3	-	1	1	11	(3.1)
<b>Total*</b>	<b>38</b>	<b>44</b>	<b>54</b>	<b>29</b>	<b>55</b>	<b>44</b>	<b>31</b>	<b>38</b>	<b>23</b>	<b>356</b>	<b>(100)</b>

<sup>#</sup> Two families had moved interstate.

\* Does not include interstate or overseas births:- two in 1993, four in 1994, six in 1995, six in 1996, five in 1997, five in 1998, four in 1999, two in 2000 and four in 2001.

Three hundred and fifty six children, born in South Australia (SA) in 1993 – 2001, had been notified to the Register by 31<sup>st</sup> December 2006. Over this same period, the Register also received 38 notifications of cases born outside SA. A comprehensive clinical assessment at the age of five years has been completed for 251 (71%) of the 356 children (see Table 1).

Experience has shown that some of the notified cases will not have cerebral palsy when assessed at five years of age; for this reason minimum and maximum rates have been calculated for the years 1993 – 2001 (Table 2). The minimum rate represents confirmed cases and the maximum reflects total ascertained cases.

**Table 2**

### Cerebral palsy ascertainment and prevalence 1993-2001

Year of birth	Live births	Ascertained cases	Confirmed cases*		Rate / 1,000 <sup>#</sup>	
					min	max
1993	19,844	38	32	(84%)	1.61	1.91
1994	19,673	44	32	(73%)	1.63	2.24
1995	19,472	54	44	(81%)	2.26	2.77
1996	18,979	29	21	(72%)	1.11	1.53
1997	18,535	55	42	(76%)	2.27	2.97
1998	18,613	44	33	(75%)	1.77	2.36
1999	18,404	31	18	(58%)	0.98	1.68
2000	17,766	38	21	(55%)	1.18	2.14
2001	17,584	23	8	(35%)	0.45	1.31
<b>1993-2001</b>	<b>168,870</b>	<b>356</b>	<b>251</b>	<b>(71%)</b>	<b>1.49</b>	<b>2.11</b>

\*Have completed comprehensive clinical assessment at around 5 years of age.

<sup>#</sup> Rate per 1,000 live births. Minimum rate represents confirmed cases and maximum rate reflects total ascertained cases.

## Notifiers to the Register

The sources of notification of children with cerebral palsy born in SA between 1993 and 2001 are shown in Table 3. Over this period, 91% of the notifications came from three main sources, Rehabilitation Specialists, Novita Children's Services and the South Australian Birth Defects Register.

**Table 3**

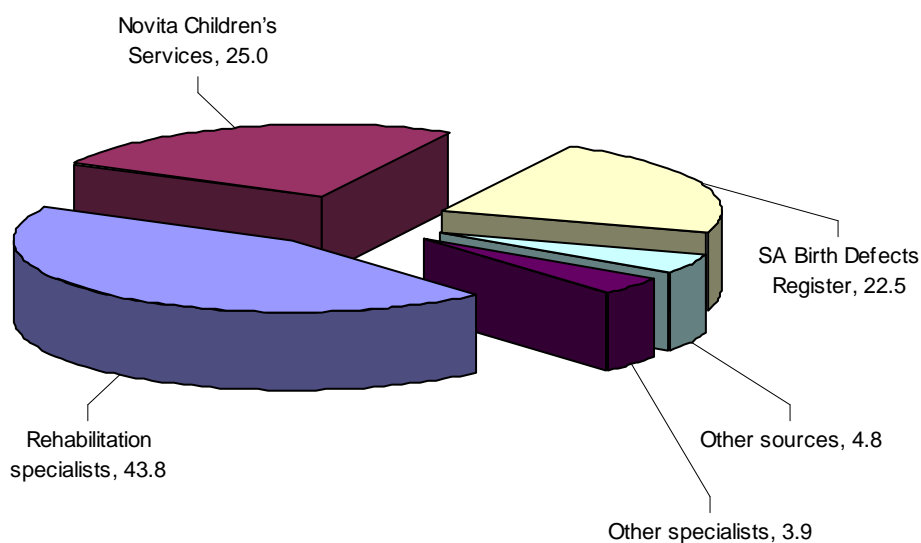
**Notifiers to the Register 1993-2001**

Notifier*	1993	1994	1995	1996	1997	1998	1999	2000	2001	1993-2001	
	No.	No.	No.	No.	No.	No.	No.	No.	No.	No.	(%)
Rehabilitation specialists	13	6	16	15	31	26	13	26	10	156	(43.8)
Novita Children's Services	14	33	26	9	2	5	-	-	-	89	(25.0)
SA Birth Defects Register	5	2	7	3	17	12	14	10	10	80	(22.5)
Other sources	3	3	5	-	1	1	1	1	2	17	(4.8)
Other specialists	3	-	-	2	4		3	1	1	14	(3.9)
<b>Total</b>	<b>38</b>	<b>44</b>	<b>54</b>	<b>29</b>	<b>55</b>	<b>44</b>	<b>31</b>	<b>38</b>	<b>23</b>	<b>356</b>	<b>(100)</b>

\*The Register encourages multiple notifications.

**Figure 1**

**Notifiers to the Register 1993-2001**



## Type of cerebral palsy

The different types of cerebral palsy for children born in SA between 1993 and 2001 are shown in Table 4. The most common forms of cerebral palsy were hemiplegia, diplegia and quadriplegia accounting for 89% of all cases.

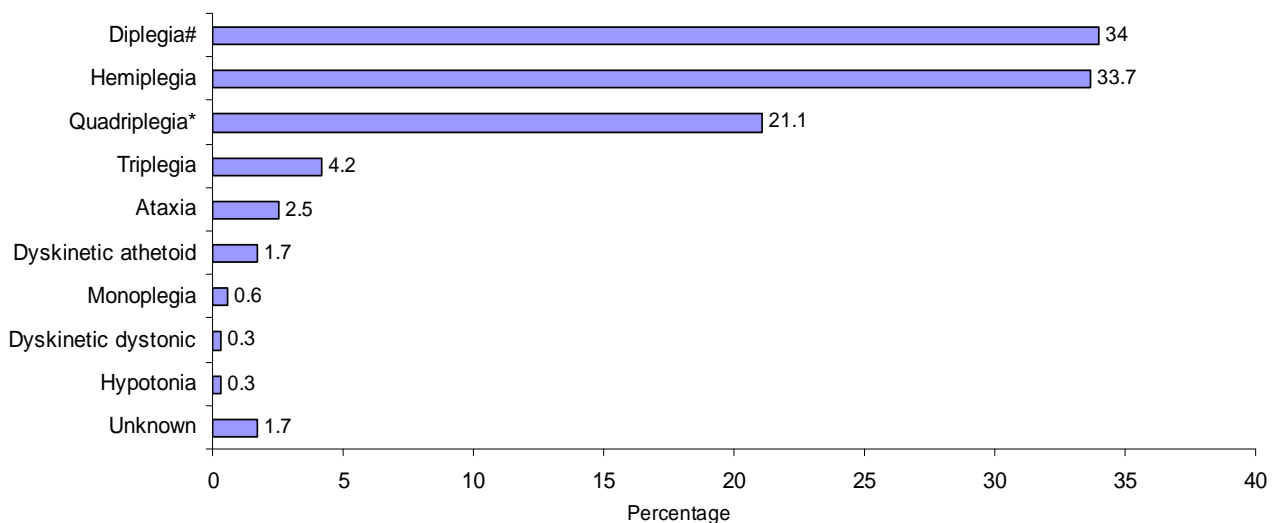
**Table 4**  
**Type of cerebral palsy 1993-2001**

Type of cerebral palsy	1993 No.	1994 No.	1995 No.	1996 No.	1997 No.	1998 No.	1999 No.	2000 No.	2001 No.	1993-2001 No.	1993-2001 (%)
Diplegia <sup>#</sup>	16	16	16	11	17	15	10	12	8	121	(34.0)
Hemiplegia	11	16	18	9	20	12	11	16	7	120	(33.7)
Quadriplegia <sup>*</sup>	7	9	11	3	9	11	9	8	8	75	(21.1)
Triplegia	2	2	4	4	3	-	-	-	-	15	(4.2)
Ataxia	1	-	1	-	1	4	1	1	-	9	(2.5)
Dyskinetic athetoid	1	-	3	1	1	-	-	-	-	6	(1.7)
Monoplegia	-	-	-	-	-	2	-	-	-	2	(0.6)
Dyskinetic dystonic	-	-	-	-	1	-	-	-	-	1	(0.3)
Hypotonia	-	-	1	-	-	-	-	-	-	1	(0.3)
Unknown	-	1	-	1	3	-	-	1	-	6	(1.7)
<b>Total</b>	<b>38</b>	<b>44</b>	<b>54</b>	<b>29</b>	<b>55</b>	<b>44</b>	<b>31</b>	<b>38</b>	<b>23</b>	<b>356</b>	<b>(100)</b>

\*Spasticity in four limbs: Upper limbs greater than or equal to lower limbs

# Spasticity in four limbs: Lower limbs greater than upper limbs

**Figure 2**  
**Type of cerebral palsy 1993-2001**



\*Spasticity in four limbs: Upper limbs greater than or equal to lower limbs

# Spasticity in four limbs: Lower limbs greater than upper limbs

## Gestational age at birth

The gestational ages at birth for cases of cerebral palsy born in SA between 1993 and 2001 are shown in Table 5. There were 51.9% of cases born prematurely (<37 weeks).

The rate of cerebral palsy by gestational age at birth 1993-2001 is also demonstrated in Table 5 and Figure 3 illustrates the association between cerebral palsy and prematurity (<37 weeks), especially gestations  $\leq 31$  weeks.

**Table 5**  
**Cerebral palsy by gestational age at birth 1993-2001**

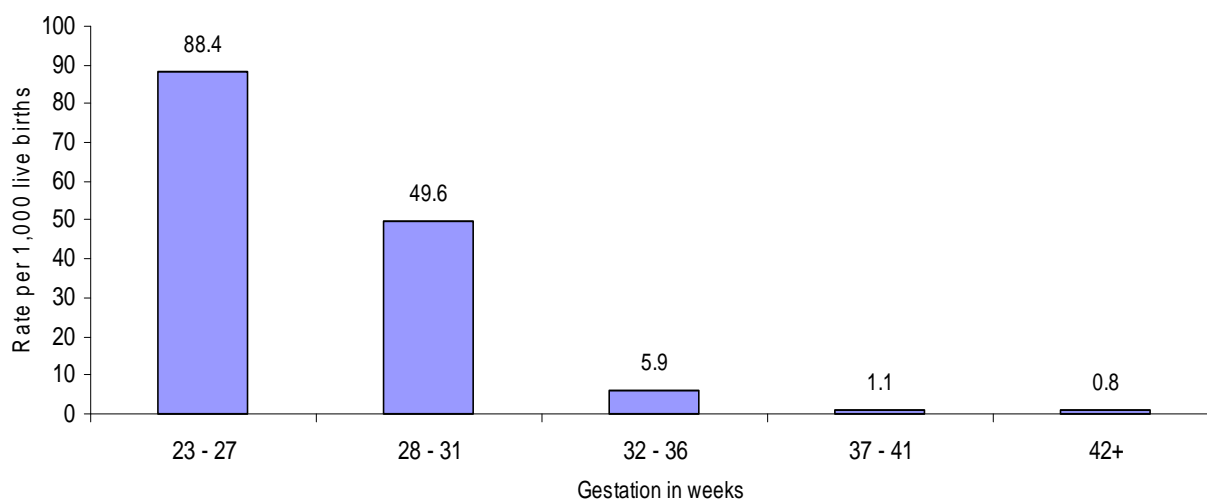
Gestation* Weeks	1993	1994	1995	1996	1997	1998	1999	2000	2001	1993-2001	1993 – 2001
	No.	No.	No.	No.	No.	No.	No.	No.	No.	No. (%)	Rate <sup>#</sup>
23 <sup>^</sup> - 27	2	6	6	8	12	13	4	3	3	57 (16.0)	88.4
28 - 31	9	7	16	3	5	7	8	9	3	67 (18.8)	49.6
32 - 36	6	8	8	3	9	8	6	8	5	61 (17.1)	5.9
37 - 41	21	23	23	14	29	16	13	18	12	169 (47.5)	1.1
42+	0	0	1	1	0	0	0	0	0	2 (0.6)	0.8
<b>Total</b>	<b>38</b>	<b>44</b>	<b>54</b>	<b>29</b>	<b>55</b>	<b>44</b>	<b>31</b>	<b>38</b>	<b>23</b>	<b>356 (100)</b>	<b>2.1</b>

\*Gestation at birth (best clinical estimate) in weeks

<sup>^</sup> There were no cases below 23 weeks

<sup>#</sup> Rate per 1,000 live births

**Figure 3**  
**Cerebral palsy by gestational age at birth 1993-2001**





## Birth weight

Weight ranges at birth from 1993-2001 are shown in Table 6 and Figure 4.

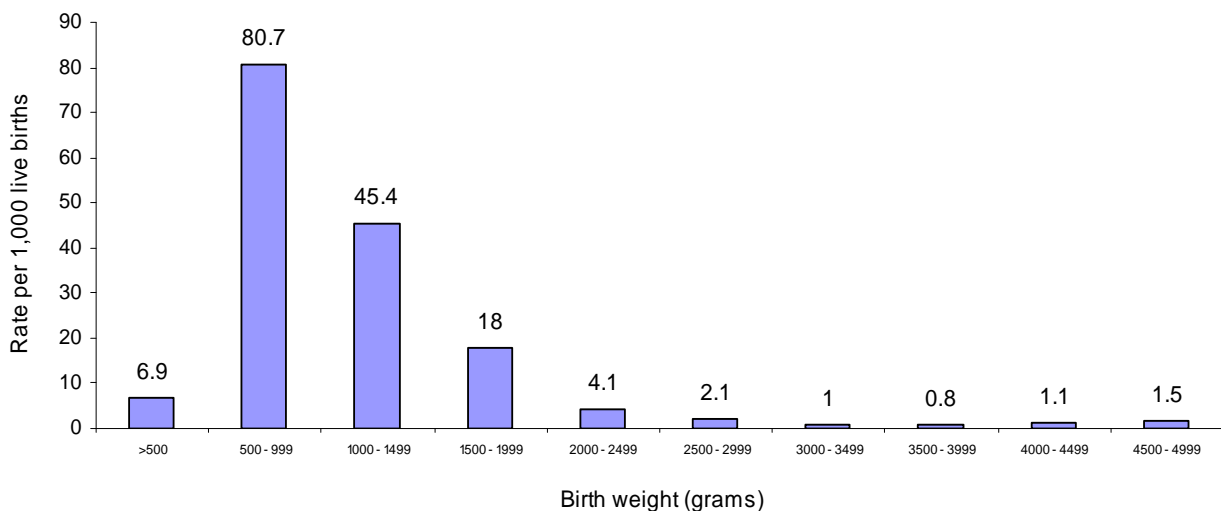
The rates of cerebral palsy per 1,000 live births, by birth weight, are provided in Table 6 and Figure 4 for the period 1993-2001. They demonstrate a strong relationship between cerebral palsy and low birth weight. As birth weight increases, the rate of cerebral palsy decreases, from 80.7 per 1,000 live births at 500 – 999 g to 0.8 per 1,000 live births at 3,500 – 3,999g.

**Table 6**  
**Cerebral palsy by birth weight 1993-2001**

Birth weight range (grams)	1993	1994	1995	1996	1997	1998	1999	2000	2001	1993-2001		1993-2001 Rate <sup>#</sup>
	No.	No.	No.	No.	No.	No.	No.	No.	No.	No.	(%)	
< 500	-	-	-	-	-	-	-	1	-	1	(0.3)	6.9
500 - 999	8	4	11	4	10	11	3	4	3	58	(16.3)	80.7
1,000 – 1,499	4	8	5	4	7	6	7	5	2	48	(13.5)	45.4
1,500 – 1,999	3	5	8	2	-	7	6	6	2	39	(11.0)	18.0
2,000 – 2,499	3	2	3	3	5	4	3	3	2	28	(7.9)	4.1
2,500 – 2,999	4	6	7	9	8	6	5	5	5	55	(15.4)	2.1
3,000 – 3,499	6	9	9	4	14	6	3	7	4	62	(17.4)	1.0
3,500 – 3,999	8	7	6	3	5	2	3	6	3	43	(12.1)	0.8
4,000 – 4,499	1	2	3	-	6	2	1	1	2	18	(5.1)	1.1
4,500 – 4,999	1	1	2	-	-	-	-	-	-	4	(1.1)	1.5
<b>Total</b>	<b>38</b>	<b>44</b>	<b>54</b>	<b>29</b>	<b>55</b>	<b>44</b>	<b>31</b>	<b>38</b>	<b>23</b>	<b>356</b>	<b>100</b>	<b>2.1</b>

<sup>#</sup> Rate per 1,000 live births

**Figure 4**  
**Rate of cerebral palsy by birth weight 1993-2001**



## Level of motor function

Tables 7-11 and Figures 5-6 present additional data collected at the 5 year assessment. As only 251 (71%) of notified cases between 1993-2001 had a clinical examination as part of the 5 year assessment, the numbers for each year are less than in the previous section of the report.

Table 7 and Figure 5 show the level of motor function for children with cerebral palsy born 1993 – 2001. The majority of children had less restricted motor function Levels I and II i.e. walking without restriction (50.6%) and walking without assistive devices (17.9%) respectively, while 30.3% were more severely affected in their motor function Levels III–V, with limitations or severe limitations to self-mobility. (A definition of motor function appears in Appendix 1).

**Table 7**

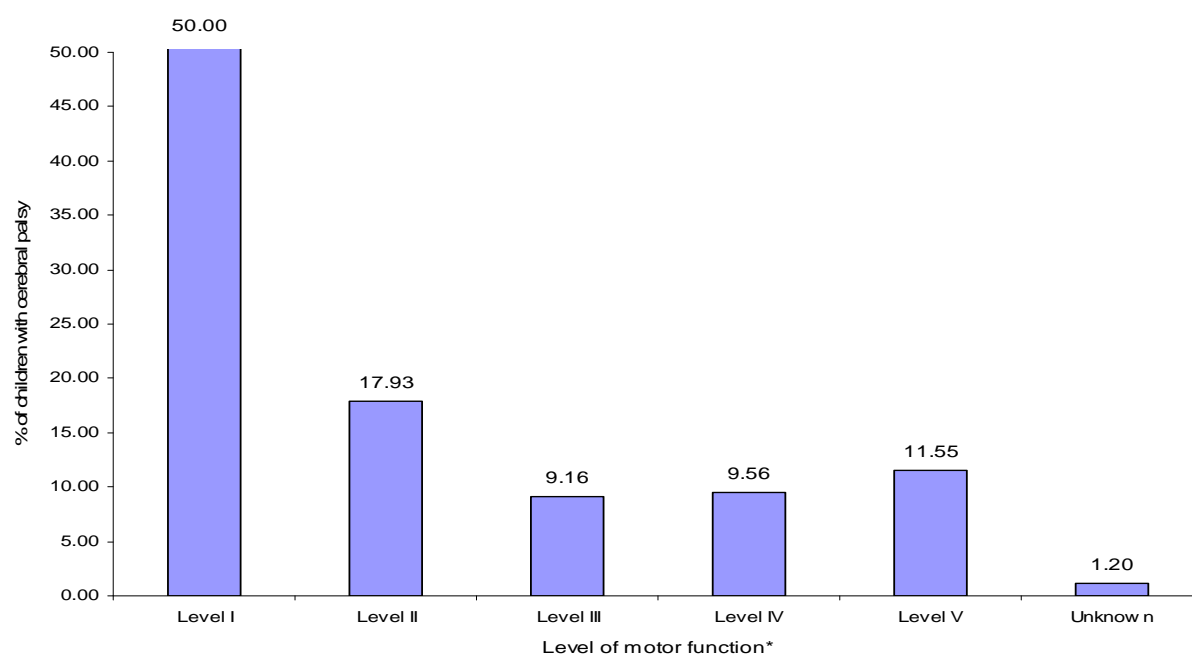
**Level of motor function 1993-2001**

Level of function*	1993	1994	1995	1996	1997	1998	1999	2000	2001	1993-2001	
	No.	No.	No.	No.	No.	No.	No.	No.	No.	No.	(%)
<b>Level I</b>	10	15	24	11	21	14	12	16	4	127	(50.6)
<b>Level II</b>	9	9	4	4	11	4	2	1	1	45	(17.9)
<b>Level III</b>	2	5	4	3	1	6	1	1	-	23	(9.2)
<b>Level IV</b>	5	1	4	2	5	1	3	2	1	24	(9.6)
<b>Level V</b>	6	2	8	1	3	7	-	-	2	29	(11.6)
<b>Unknown</b>	-	-	-	-	1	1	-	1	-	3	(1.2)
<b>Total</b>	<b>32</b>	<b>32</b>	<b>44</b>	<b>21</b>	<b>42</b>	<b>33</b>	<b>18</b>	<b>21</b>	<b>8</b>	<b>251</b>	<b>(100)</b>

\* Definition of motor function appears in Appendix 1.

**Figure 5**

**Level of motor function 1993-2001**



\* Definition of motor function appears in Appendix 1.

## Co-morbidities

Table 8 and Figure 6 illustrate the level of intellectual ability for children with cerebral palsy born 1993 – 2001. They show that 47% of children with cerebral palsy had average or greater intellectual abilities (i.e. an intelligent quotient score of  $\geq 90$ ), 15.5% of children had low average (70-89 I.Q.), 15.1% had mild intellectual disability, and 16.7% had moderate to profound intellectual disability. Various scales, appropriate to the child's age and physical abilities, were used to assess intellectual ability.

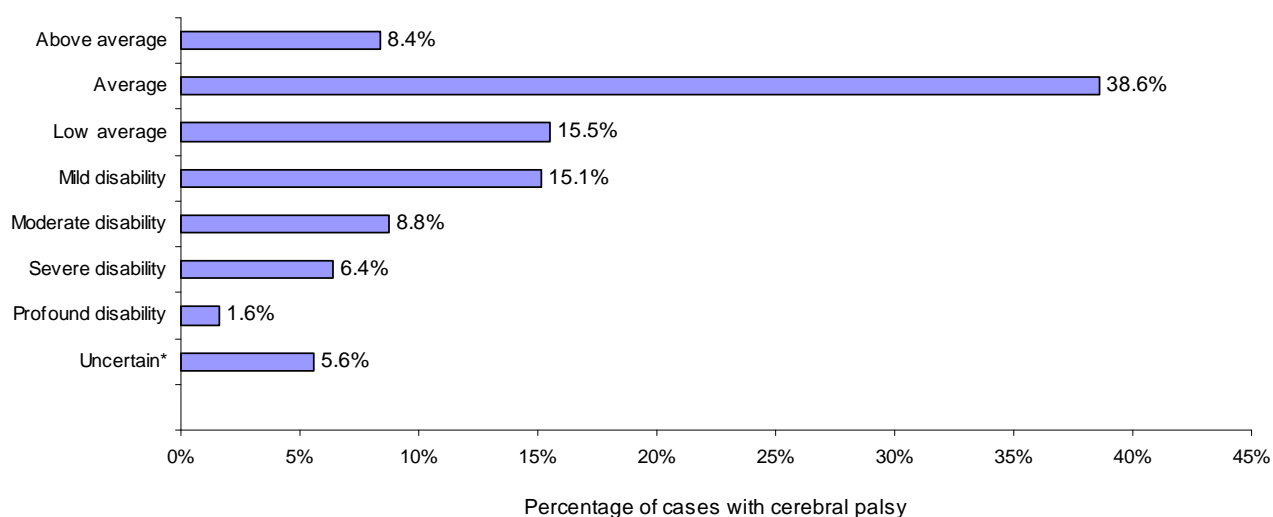
**Table 8**  
**Intellectual ability 1993-2001**

Intellectual ability #	1993	1994	1995	1996	1997	1998	1999	2000	2001	1993-2001	
	No.	No.	No.	No.	No.	No.	No.	No.	No.	No.	(%)
Above average	-	3	2	-	3	6	2	4	1	21	(8.4)
Average	10	8	14	12	20	10	9	11	3	97	(38.6)
Low average	6	6	8	5	4	5	2	2	1	39	(15.5)
Mild disability	3	9	10	2	7	5	1	1	-	38	(15.1)
Moderate disability	7	3	3	-	6	2	-	-	1	22	(8.8)
Severe disability	5	2	2	1	2	1	1	1	1	16	(6.4)
Profound disability	1	1	-	-	-	1	1	-	-	4	(1.6)
Uncertain*	-	-	5	1	-	3	2	2	1	14	(5.6)
<b>Total</b>	<b>32</b>	<b>32</b>	<b>44</b>	<b>21</b>	<b>42</b>	<b>33</b>	<b>18</b>	<b>21</b>	<b>8</b>	<b>251</b>	<b>(100)</b>

\*Not possible to determine intellectual ability.

#Various scales, appropriate to the child's age and physical abilities, were used to assess intellectual ability.

**Figure 6**  
**Intellectual ability # 1993-2001**



\*Not possible to determine intellectual ability.

#Various scales, appropriate to the child's age and physical abilities, were used to assess intellectual ability.

## Co-morbidities

The frequency of visual problems in children with cerebral palsy born 1993 – 2001 is shown in Table 9. 51.8% of children had normal vision and 37.8% had impaired vision. In 7.6% of cases it was uncertain whether a visual problem was present because of difficulty in assessment e.g. due to the level of intellectual disability. Impaired vision includes; strabismus +/- amblyopia, refractive error, cortical blindness, nystagmus and optic nerve abnormalities.

**Table 9**

### Vision 1993-2001

Vision*	1993	1994	1995	1996	1997	1998	1999	2001	2001	1993-2001
	No.	No.	No.	No.	No.	No.	No.	No.	No.	No. (%)
Normal	15	14	22	17	27	11	4	15	5	130 (51.8)
Impaired	13	15	16	4	12	17	11	5	2	95 (37.8)
Uncertain	4	1	5	-	2	4	1	1	1	19 (7.6)
Unknown		2	1	-	1	1	2	-	-	7 (2.8)
<b>Total</b>	<b>32</b>	<b>32</b>	<b>44</b>	<b>21</b>	<b>42</b>	<b>33</b>	<b>18</b>	<b>21</b>	<b>8</b>	<b>251 (100)</b>

\* Impaired vision includes; strabismus +/- amblyopia, refractive error, cortical blindness, nystagmus and optic nerve abnormalities.

The frequency of hearing problems in children with cerebral palsy born 1993 – 2001 is shown in Table 10. 82.9% of children had normal hearing and 12.7% of cases had impaired hearing. In 2.0% of cases the level of hearing was uncertain and in 2.4% of cases it was unknown. Impaired hearing includes; sensorineural and/or conductive hearing loss determined by audiology.

**Table 10**

### Hearing 1993-2001

Hearing*	1993	1994	1995	1996	1997	1998	1999	2000	2001	1993-2001
	No.	No.	No.	No.	No.	No.	No.	No.	No.	No. (%)
Normal	25	24	34	19	35	29	17	18	7	208 (82.9)
Impaired	6	6	8	2	4	3	1	1	1	32 (12.7)
Uncertain	1	2	1	-	1	-	-	-	-	5 (2.0)
Unknown	-	-	1	-	2	1	-	2	-	6 (2.4)
<b>Total</b>	<b>32</b>	<b>32</b>	<b>44</b>	<b>21</b>	<b>42</b>	<b>33</b>	<b>18</b>	<b>21</b>	<b>8</b>	<b>251 (100)</b>

\*Impaired hearing includes; sensorineural and/or conductive hearing loss determined by audiology.

## Co-morbidities

Table 11 reveals the types of cerebral palsy with associated co-morbidities of hearing, vision, epilepsy and intellectual disability. Some differences can be seen, for example between quadriplegic and diplegic types of cerebral palsy, especially with respect to vision, epilepsy and intellectual disability. The proportions of these co-morbidities were found to be significantly higher in those with quadriplegia. Some of the children have multiple co-morbidities, therefore the totals do not add to 100%. Intellectual disability is defined as mild to profound disability (I.Q. <70).

**Table 11**

**Type of cerebral palsy and associated disabilities**

Type of cerebral palsy	Total in category	Hearing Impairment		Vision Impairment		Epilepsy		Intellectual disability*	
		No.	(%)	No.	(%)	No.	(%)	No.	(%)
Quadriplegia	36	4	(11)	24	(67)	22	(61)	22	(61)
Triplegia	13	2	(15)	4	(31)	2	(15)	4	(31)
Right hemiplegia	49	9	(18)	17	(35)	14	(29)	9	(18)
Left hemiplegia	41	5	(12)	11	(27)	13	(32)	13	(32)
Diplegia	96	10	(10)	32	(33)	15	(16)	25	(26)
Monoplegia	1	-	-	-	-	-	-	-	-
Ataxia	7	1	(14)	4	(57)	2	(29)	4	(57)
Dyskinetic athetoid	6	-	-	2	(33)	1	(17)	2	(33)
Dyskinetic dystonic	1	-	-	-	-	1	(100)	-	-
Hypotonia	1	1	(100)	1	(100)	-	-	1	(100)
<b>Total (% of total)</b>	<b>251</b>	<b>32</b>	<b>(13)</b>	<b>95</b>	<b>(38)</b>	<b>70</b>	<b>(28)</b>	<b>80</b>	<b>(32)</b>

\* Known to have mild to profound intellectual disability.

\* Some of the children have multiple co-morbidities, therefore the totals do not add to 100%.

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## Presentations / Conferences / Publications

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### Conferences

#### Conference presentations utilising data from the register

CS Gibson, AH MacLennan, PN Goldwater, EA Haan, K Priest, GA Dekker. Mannose binding lectin haplotypes are associated with cerebral palsy. Perinatal Society of Australia and New Zealand Conference, Melbourne, Australia, 2007 (oral presentation).

CS Gibson, AH MacLennan, PN Goldwater, GA Dekker. Antenatal causes of cerebral palsy: investigating associations between inherited thrombophilia, cytokine polymorphisms and viral infections. Healthy Development Adelaide Early Career Research Symposium, Adelaide, Australia 2006 (oral presentation).

CS Gibson, AH MacLennan, PN Goldwater, K Priest, GA Dekker. Cytokine polymorphisms are associated with adverse pregnancy outcomes. Perinatal Society of Australia and New Zealand Conference, Perth, Australia, 2006 (oral presentation). Winner of the 2006 PSANZ New Investigator Award for an excellent presentation at the PSANZ 2006 National Congress.

CS Gibson, AH MacLennan, PN Goldwater, EA Haan, K Priest, GA Dekker. The role of fetal viral infection in the development of adverse pregnancy outcomes. Society for Maternal Fetal Medicine Conference, Miami, USA, 2006 (poster presentation).

CS Gibson, NG Janssen, WJ Kist, AH MacLennan, WM Hague, EA Haan, PN Goldwater, K Priest, GA Dekker. The role of fetal inherited thrombophilia in the development of adverse pregnancy outcomes. Society for Maternal Fetal Medicine Conference, Miami, USA, 2006 (concurrent oral presentation).

CS Gibson, AH MacLennan, PN Goldwater, EA Haan, K Priest, GA Dekker. The association between inherited cytokine polymorphisms and cerebral palsy. Society for Maternal Fetal Medicine Conference, Miami, USA, 2006 (plenary oral presentation).

CS Gibson, AH MacLennan, PN Goldwater, E Haan, K Priest, GA Dekker. Human herpesviruses increase the risk of developing cerebral palsy. Perinatal Society of Australia and New Zealand Conference, Adelaide, Australia, 2005 (oral presentation). Winner of the 2005 PSANZ/Perinatal Research Society Award for an outstanding presentation at the PSANZ 2005 National Congress.

Russo R, Murchland S, Sandelance M, Flett P, Brook P. Functional outcomes in children injected with botulinum toxin. Improving the upper limb to enhance participation level function in children with spasticity and dystonia. AusACPDM conference, 18<sup>th</sup>-20<sup>th</sup> March 2004 (poster presentation).

CS Gibson, AH MacLennan, WM Hague, Z Rudzki, P Sharpe, A Chan, GA Dekker. MTHFR C677T and Factor V Leiden thrombophilic polymorphisms are risk factors for cerebral palsy. Australian Society for Medical Research Conference, SA Branch, Adelaide Australia 2004 (oral presentation).

CS Gibson, AH MacLennan, WM Hague, Z Rudzki, P Sharpe, A Chan, GA Dekker. Fetal thrombophilic polymorphisms are not a risk factor for cerebral palsy. Perinatal Society of Australia and New Zealand Conference, Sydney, Australia, 2004 (oral presentation).

CS Gibson, AH MacLennan, WM Hague, Z Rudzki, P Sharpe, A Chan, GA Dekker. Fetal thrombophilic polymorphisms are not a risk factor for cerebral palsy. Society for Maternal Fetal Medicine Conference, New Orleans, USA, 2004 (oral presentation).

CS Gibson, AH MacLennan, WM Hague, Z Rudzki, P Sharpe, A Chan, GA Dekker. Fetal thrombophilic polymorphisms are not a risk factor for cerebral palsy. Medicine and Pregnancy Conference, Fremantle, Western Australia, p32 (2003) (oral presentation).

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## Presentations / Conferences / Publications

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### Conferences attended by register staff

Australian National Cerebral Palsy Register's State and Territory Representatives Conference, Telethon Institute For Child Health Research, Perth, 16<sup>th</sup> -17<sup>th</sup> May 2005 (P. Flett, K. Tungaraza, P. van Essen, H. Scott).

Australian Cerebral Palsy Association national conference, Adelaide, 14<sup>th</sup> -15<sup>th</sup> March 2005 (P. Flett).

National Cerebral Palsy Register meeting, Sydney, 3<sup>rd</sup> -4<sup>th</sup> April 2003 (P. Flett, K. Tungaraza, P. Sharpe, H. Scott).

Australian Cerebral Palsy Register meeting, Brisbane, 30<sup>th</sup> -31<sup>st</sup> October 2006 (H. Scott).

### Publications utilising data from the Register

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.

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.

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, 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.

MacLennan A, Nelson KB, Hankins G, Speer M. Who will deliver our grandchildren? Implications of cerebral palsy litigation. *JAMA* 2005;294:1688-90.

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.

Scher AI, Petterson B, Blair E, Ellenberg JH, Grether JK, Haan EA, Reddihough D, Yeargin-Allsopp M and Nelson KB. The risk of mortality or cerebral palsy in twins: A collaborative population-based study. *Pediatr Res* 2002;52:671-81.

### Annual Reports

1999 - 2006 Annual Report of the South Australian Cerebral Palsy Register.

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## Appendix 1

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### GROSS MOTOR FUNCTION CLASSIFICATION SYSTEM IN CEREBRAL PALSY <sup>6</sup>

#### LEVEL I

Walks without restrictions: limitations in more advanced gross motor skills.

**Before 2nd birthday:** Infants move in and out of sitting and floor sit with both hands free to manipulate objects. Infants crawl on hands and knees, pull to stand and take steps holding onto furniture. Infants walk between 18 months and 2 years of age without the need for any assistive mobility device.

**From age 2 to 4th birthday:** Children floor sit with both hands free to manipulate objects. Movements in and out of floor sitting and standing are performed with adult assistance. Children walk as the preferred method of mobility without the need for any assistive mobility device.

**From age 4 to 6th birthday:** Children get into and out of and sit in a chair without the need for hand support. Children move from the floor and from chair sitting to standing without the need for objects for support. Children walk indoors and outdoors, and climb stairs. Emerging ability to run and jump.

**From age 6 to 12:** Children walk indoors and outdoors and climb stairs without limitations. Children perform gross motor skills including running and jumping but speed; balance and coordination are reduced.

#### LEVEL II

Walks without assistive devices: limitations walking outdoors and in the community.

**Before 2nd birthday:** Infants maintain floor sitting but may need to use their hands for support to maintain balance. Infants creep on their stomach or crawl on hands and knees. Infants may pull to stand and take steps holding onto furniture.

**From age 2 to 4th birthday:** Children floor sit but may have difficulty with balance when both hands are free to manipulate objects. Movements in and out of sitting are performed without adult assistance. Children pull to stand on a stable surface. Children crawl on hands and knees with a reciprocal pattern, cruise holding onto furniture and walk using an assistive mobility device as preferred methods of mobility.

**From 4 to 6th birthday:** Children sit in a chair with both hands free to manipulate objects. Children move from the floor to standing and from chair sitting to standing but often require a stable surface to push or pull up on with their arms. Children walk without the need for any assistive mobility device indoors and for short distances on level surfaces outdoors. Children climb stairs holding onto a railing but are unable to run or jump.

**From age 6 to 12:** 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. Children have at best only minimal ability to perform gross motor skills such as running and jumping.

#### *Distinction between Levels I and II*

*Compared with children in Level I, children in Level II have limitations in the ease of performing movement transitions: walking outdoors and in the community: the need for assistive mobility devices when beginning to walk: quality of movement: and the ability to perform gross motor skills such as running and jumping.*

#### LEVEL III

Walks with assistive mobility devices: limitations walking outdoors and in the community.

**Before 2nd birthday:** Infants maintain floor sitting when the low back is supported. Infants roll and creep forward on their stomachs.

**From age 2 to 4th birthday:** Children maintain floor sitting often by 'W-sitting' (sitting between flexed and internally rotated hips and knees) and may require adult assistance to assume sitting. Children creep on their stomach or crawl on hands and knees (often without reciprocal leg movements) as their primary methods of self-mobility. Children may pull to stand on a stable surface and cruise short distances. Children may walk short distances indoors using an assistive mobility device and adult assistance for steering and turning.

**From age 4 to 6th birthday:** Children sit on a regular chair but may require pelvic or trunk support to maximise hand function. Children move in and out of chair sitting using a stable surface to push on or pull up with their arms. Children walk with an assistive mobility device on level surfaces and climb stairs with



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## Appendix 1 (continued)

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assistance from an adult. Children frequently are transported when travelling for long distances or outdoors on uneven terrain.

**From age 6 to 12:** Children walk indoors or outdoors on a level surface with an assistive mobility device. Children may climb stairs holding onto a railing. Depending on upper limb function, children propel a wheelchair manually or are transported when travelling for long distances or outdoors on uneven terrain.

### ***Distinction between Levels II and III***

*Differences are seen in the degree of achievement of functional mobility. Children in Level III need assistive mobility devices and frequently orthoses to walk, while children in Level II do not require assistive mobility devices after age 4.*

### **LEVEL IV**

Self-mobility with limitations: children are transported or use power mobility outdoors and in the community.

**Before the 2nd birthday:** Infants have head control but trunk support is required for floor sitting. Infants can roll to supine and may roll to prone.

**From age 2 to 4th birthday:** Children floor sit when placed, but are unable to maintain alignment and balance without use of their hands for support. Children frequently require adaptive equipment for sitting and standing. Self-mobility for short distances (within a room) is achieved through rolling, creeping on stomach, or crawling on hands and knees without reciprocal leg movement.

**From age 4 to 6th birthday:** Children sit on a chair but need adaptive seating for trunk control and to maximise hand function. Children move in and out of chair sitting with assistance from an adult or a stable surface to push or pull up on with their arms. Children may at best walk short distances with a walker and adult supervision but have difficulty turning and maintaining balance on uneven surfaces. Children are transported in the community. Children may achieve self-mobility using a power wheelchair.

**From age 6 to 12:** Children may maintain levels of function achieved before age 6 or rely more on wheeled mobility at home, school, and in the community. Children may achieve self-mobility using a power wheelchair.

### ***Distinction between Levels III and IV***

*Differences in sitting ability and mobility exist, even allowing for extensive use of assistive technology. Children in Level III sit independently, have independent floor mobility and walk with assistive mobility devices. Children in Level IV function in sitting (usually supported) but independent mobility is very limited. Children in Level IV are more likely to be transported or use power mobility.*

### **LEVEL V**

Self-mobility is severely limited even with the use of assistive technology.

**Before 2nd birthday:** Physical impairments limit voluntary control of movement. Infants are unable to maintain antigravity head and trunk postures in prone and sitting. Infants require adult assistance to roll.

**From age 2 to 12:** Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology. At Level V, children have no means of independent mobility and are transported. Some children achieve self-mobility using a power wheelchair with extensive adaptations.

### ***Distinctions between Levels IV and V***

*Children in Level V lack independence even in basic antigravity postural control. Self-mobility is achieved only if the child can learn how to operate an electrically powered wheelchair. (Palisano et al, 1997)<sup>6</sup>.*

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## Appendix 2

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### South Australian Cerebral Palsy Register Family Information Sheet

#### About the South Australian Cerebral Palsy Register

Approximately one in every 500 children born in South Australia has cerebral palsy. It is now recognised that most cerebral palsy is due to factors present before labour begins, and not as a result of events occurring during labour and delivery. However, what actually causes cerebral palsy is not clear. In order to determine these factors and to improve services, it is important to collect information about children with cerebral palsy.

For several years, doctors caring for children with cerebral palsy in South Australia discussed the possibility and value of establishing a cerebral palsy register. In 1991, a steering committee was formed which included doctors from Spastic Centres of SA, Novita Children's Services, Flinders Medical Centre, and the Children, Youth and Women's Health Service. The South Australian Cerebral Palsy Register was established in 1997 with support from Novita Children's Services, Community Accommodation and Respite Agency (CARA), Rotary, and the Children, Youth and Women's Health Service. The Register is located at, and receives its funding from the Children, Youth and Women's Health Service.

#### What is the purpose of the Register?

The purpose of the Cerebral Palsy Register is to collect information about South Australian children with cerebral palsy. This information will enable us to:

- Find out how many children in South Australia have cerebral palsy;
- Detect changes in the number of children with cerebral palsy;
- Carry out research into the causes of cerebral palsy;
- Identify the full range of disabilities experienced by children with cerebral palsy;
- Help in the planning of services for children with cerebral palsy and;
- Increase knowledge in the community about cerebral palsy.

#### What benefits are there for my child?

At five years of age your child will receive a free, comprehensive clinical assessment by a specialist paediatrician. This assessment will take approximately 45 minutes. Information gained by the paediatrician may be used to make recommendations to your child's doctor about services or treatment. You will receive information of interest to you, including information about current research and the option to receive a copy of the Register's Annual Report.

#### What other benefits may come from participating?

By participating you will also benefit other children with cerebral palsy by contributing to research. Such research may:

- Find ways of preventing cerebral palsy;
- Find possible causes;
- Lead to new treatments or management strategies;
- Increase community awareness and recognition and;
- Lead to the development of new and/or improved services.

#### Who are the Register staff we will have contact with?

The person with whom you will have the most contact will be the Register Officer of the South Australian Cerebral Palsy Register. Dr Ray Russo, Dr Andrew Tidemann, Dr Deirdre White and Dr Phil Egan are the specialist rehabilitation paediatricians who work with the Register. One of these paediatricians will conduct your child's clinical assessment.

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## Appendix 2 (continued)

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### **How will information about my child be kept confidential?**

All information contained on the South Australian Cerebral Palsy Register is strictly confidential. Only Register staff and those carrying out research in collaboration with them will use it. This means that no information, which identifies your child, will be released to other people unless you give written permission.

### **Are there any risks for my child?**

There are no risks for your child associated with the medical assessment at five years of age. It will **not** involve the taking of blood samples or any other invasive tests.

### **Has the Register received approval from an Ethics Committee?**

The South Australian Cerebral Palsy Register has received approval from the Research Ethics Committees of the Children, Youth and Women's Health Service, Flinders Medical Centre, and the North Western Adelaide Health Service.

### **How do I give my consent?**

You will be asked to give written consent to include your child on the Register. If, in the future, you change your mind, you can withdraw your consent. Refusing to include your child will not disadvantage your child in any way or change your relationship with health professionals or hospitals.

### **What happens now?**

By now you will have received some information from your child's doctor about the South Australian Cerebral Palsy Register, and the Register Officer will have contacted you either by phone or letter.

The next step is to decide whether you would like your child to be included on the Register. If you decide that you would like your child to be included then you will be asked to sign a Consent Form and return it to the Register. When your child is five years old, a paediatric rehabilitation specialist will conduct a medical assessment. This will usually be conducted at your **Novita Regional Office** and will take approximately 45 minutes. It may be possible to make other arrangements for country families and those who would find it difficult to get to the Children, Youth and Women's Health Service. The medical assessment will be conducted free of charge. You will receive no payment for your participation.

Although doctors working with the Cerebral Palsy Register will conduct the medical assessment, your child will remain in the care of their usual doctor. If, at any time, you have any questions about your child's treatment or development you should ask your child's usual doctor. Between your child's inclusion on the Register and their five year assessment, the Register Officer will maintain contact with you.

To collect complete information about your child's health it may be necessary to consult hospital records of your child's birth and current health (all of these options are explained on the Consent Form).

If you have any further questions please contact the Register Officer, South Australian Cerebral Palsy Register, on (08) 8161 7242 during office hours.

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## References

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