

Cerebral Palsy in South Australia 2015

South Australian Cerebral Palsy Register
Women's & Children's Hospital
Adelaide, South Australia



Government
of South Australia
SA Health



Women's
& Children's
Hospital

Cerebral Palsy in South Australia 2015



Children born 1993 to 2010 with cerebral palsy
notified by 31st December 2015
to the South Australian Cerebral Palsy Register
(part of The South Australian Birth Defects Register)

(provisional data provided for children born between 2011 and 2015)

Location

Health Informatics, Planning, Performance Outcomes (HIPPO) Unit
Women's and Children's Hospital
Women's and Children's Health Network
2nd Floor Michell Building
72 King William Road
North Adelaide, South Australia 5006
Telephone: (08) 8161 7242
Email: cregister@sa.gov.au
Website: http://www.wch.sa.gov.au/services/az/other/phru/cerebral_palsy.html

Register Staff

Dr Wendy Scheil *Public Health Physician*
Dr Catherine Gibson *Manager, SA Birth Defects Register*
Ms Heather Scott *Manager, SA Birth Defects Register*
Mrs Rosie Rice *Register Officer, SA Cerebral Palsy Register*

Register Management Group

Dr Wendy Scheil *Representing SA Department of Health, Epidemiology Branch*
A/Prof Remo (Ray) Russo *Paediatric Rehabilitation Specialist*
Dr Catherine Gibson *Manager, SA Birth Defects Register*
Ms Heather Scott *Manager, SA Birth Defects Register*
Mrs Rosie Rice *Register Officer, SA Cerebral Palsy Register*

Specialist Advisors to the Register

Dr James Rice *Paediatric Rehabilitation Specialist*
Dr Andrew Tidemann *Paediatric Rehabilitation Specialist*
Dr Deirdre White *Developmental Paediatrician*
Ms Terry Lyons *General Manager, Statewide Services, Novita Children's Services*
A/Prof Ross Haslam *Neonatologist, Neonatal Follow-Up Program, WCH*
A/Prof Peter Marshall *Neonatologist, Neonatal Follow-Up Program, FMC*

Collaborating Organisations

Novita Children's Services
Flinders Medical Centre
Women's and Children's Health Network

Funding

The Register is funded by the Women's and Children's Health Network, with additional support provided by Novita Children's Services of South Australia

Suggested Citation

Scott H, Gibson CS, Rice R, Scheil W. Cerebral Palsy in South Australia 2015. Adelaide. SA Cerebral Palsy Register, Women's and Children's Health Network.

ISSN 2205-0744 (print)
ISSN 2205-0752 (online)

Contents

Executive Summary.....	5
Thanks to notifiers / Acknowledgements.....	6
South Australian Cerebral Palsy Register staff.....	7
What is cerebral palsy?.....	8
Cerebral Palsy terminology.....	9
Funding / Administration / Ethical approval / Legislative framework.....	10
Aims of the Register.....	10
How the Register works.....	11
Prevalence of cerebral palsy 1993 - 2010.....	12
Notifiers to the Register.....	13
Type of cerebral palsy.....	14
Plurality and sex of child.....	15
Gestational age at birth.....	16
Birth weight.....	17
Level of motor function.....	18
Level of motor function by type of cerebral palsy.....	19
Co-morbidities.....	20
Provisional data for children born 2011 - 2015.....	23
References.....	24
Publications and Presentations.....	24

Tables, Figures and Appendices

Tables and Figures

All notified children with cerebral palsy born in South Australia 1993 - 2010

Table 1:	Children with cerebral palsy ascertained by the Register.....	12
Table 2:	Cerebral palsy ascertainment and prevalence	12
Table 3:	Notifiers to the Register.....	13
Table 4:	Type of cerebral palsy	14
Table 5:	Cerebral palsy by plurality.....	15
Table 6:	Cerebral palsy by sex.....	15
Table 7:	Cerebral palsy by gestational age at birth	16
Table 8:	Cerebral palsy by birth weight.....	17
Figure 1:	Notifiers to the Register.....	13
Figure 2:	Type of cerebral palsy.....	14
Figure 3:	Cerebral palsy by plurality.....	15
Figure 4:	Cerebral palsy by sex.....	15
Figure 5:	Cerebral palsy by gestational age at birth.....	16
Figure 6:	Cerebral palsy by birth weight.....	17

Children with cerebral palsy born in South Australia and assessed at 5 years of age 1993 - 2010

Table 9:	Gross Motor Function Classification.....	18
Table 10:	Level of motor function by type of cerebral palsy.....	19
Table 11:	Intellectual ability.....	20
Table 12:	Vision.....	21
Table 13:	Hearing.....	21
Table 14:	Epilepsy.....	21
Table 15:	Speech.....	22
Table 16:	Type of cerebral palsy and associated disabilities.....	22
Figure 7:	Gross Motor Function Classification.....	18
Figure 8:	Level of motor function by type of cerebral palsy	19
Figure 9:	Intellectual ability.....	20

Provisional data for children with cerebral palsy born in South Australia 2011 - 2015

Table 17:	Provisional data for SA children with cerebral palsy 2011 - 2015.....	23
------------------	---	----

Appendices

Appendix 1:	Gross Motor Function Classification System in cerebral palsy.....	25
Appendix 2:	South Australian Cerebral Palsy Register Family Information Sheet.....	27

Executive Summary

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 18,746 live births per year (1993 – 2010). This report presents information for children with cerebral palsy born in the years 1993 – 2010.

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, generally taken to be before 2 years of age. Individuals with cerebral palsy have lifelong motor disabilities, frequently associated with intellectual disability, epilepsy and visual and hearing impairment. It is the most common chronic motor disability of childhood and it places a large emotional and financial burden on both those affected and their families.

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

If parents consent, at around five years of age, a comprehensive medical history is obtained and the children are offered 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 extent of disabilities experienced by the child.

For the years 1993 – 2010, 676 children with cerebral palsy were ascertained. At 31st December 2015, 95.1% (482/507) of children who were eligible to be assessed had completed their comprehensive five year assessment. For various reasons, there were 169 cases that were not able to complete a clinical assessment (18 had died before the age of five years, 36 did not want to participate in the register and 115 were not able to be contacted).

Between 1993 and 2010 the minimum prevalence of cerebral palsy was 1.43 per 1,000 live births, and the maximum was 2.00 per 1,000 live births. The minimum prevalence estimate represents the cases assessed at five years, and the maximum prevalence estimate reflects the total ascertained cases.

Paediatric rehabilitation specialists notified 56% of cases, the South Australian Birth Defects Register 22%, Novita Children's Services 14%, other specialists 4% and other sources 4%.

The types of cerebral palsy are based on clinical features. Hemiplegia (38%) and diplegia (31%) were the most common forms of cerebral palsy, followed by quadriplegia (20%), ataxia (3%) and triplegia (2%). Dyskinetic athetosis, dyskinetic dystonia, hypotonia and monoplegia were less common forms of the disorder. In 1% of cases, the type of cerebral palsy was unknown.

Singleton pregnancies accounted for 89% of affected children and 11% were born from multiple pregnancies.

The percentage of males with cerebral palsy was 57%, compared with the South Australian population, where 51% of liveborn babies are males.

Birth at term (\geq 37 weeks gestation) accounted for 53% of affected children, while 47% were born prematurely ($<$ 37 weeks gestation).

The association of premature birth with cerebral palsy was strong. The prevalence among live births born at 23-27 weeks gestation was 64.7 cases per 1,000 live births, compared with only 1.2 cases per 1,000 live births at term (\geq 37 weeks gestation). Consistent with the association with premature birth, low birth weight is also strongly associated with cerebral palsy; the prevalence being 66.7 cases per 1,000 live births with birth weights in the range 500-999 grams, but only 0.9 per 1,000 among live births in the range 3500-3999 grams.

Of the 482 children assessed, 65% had relatively good levels of gross motor function (levels I and II), while 34% had more severely affected gross motor function (levels III-V).

The prevalence of co-morbidities associated with cerebral palsy included 33% with impaired intellectual ability (mild to severe impairment), 37% with impaired vision and 6% with impaired hearing. A diagnosis of epilepsy was made for 27% of assessed children. Speech was assessed as being normal in 44% of children, with 42% of children displaying some level of speech impairment. 13% of children were non-verbal.

Thanks to Notifiers

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 Paediatric Rehabilitation Service of the Women's and Children's Health Network.

We would especially like to thank and acknowledge all the Rehabilitation Specialists and paediatricians who complete the Data Collection Form, with special thanks in particular to A/Prof Ray Russo, Dr James Rice and Dr Andrew Tidemann.

We acknowledge the ongoing assistance of the staff of the Medical Records Departments at Flinders Medical Centre, Lyell McEwin Health Service and Women's and Children's Health Network.

Special thanks must also go to staff of the Pregnancy Outcome Statistics Unit of the Epidemiology Branch, SA Health, for their invaluable assistance.

Acknowledgements

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)
- The Community Accommodation and Respite Agency (CARA)
- Paediatricians from specialist centres and in private practice
- Staff of the Paediatric Rehabilitation Service of the Women's and Children's Health Network
- Long term follow up program coordinators from the Women's and Children's Health Network and Flinders Medical Centre
- Staff of the South Australian Clinical Genetics Service of SA Pathology

While there are many who have contributed to the South Australian 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 years.

South Australian Cerebral Palsy Register Staff



Left to Right:

Mrs Rosie Rice, Ms Heather Scott, Dr Catherine Gibson, Dr Wendy Scheil

What is Cerebral Palsy?

Cerebral palsy is a descriptive term applied to a group of motor disorders of central (brain) origin defined by a clinical description¹. 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).

Approximately 2 in every 1,000 children born in South Australia have cerebral palsy, which equates to approximately 38 newly diagnosed children on average each year for the period 1993 – 2010. Despite improvements in antenatal, intrapartum and postnatal care, there has been little change in the incidence of cerebral palsy over many years.

Cerebral palsy affects an individual's ability to control movement and posture. Whilst the word "palsy" means "paralysis", a more accurate description of the muscle symptoms experienced by sufferers of cerebral palsy might be weakness (paresis) and an inability to make controlled 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 in quality of life.

Children affected by cerebral palsy will have lifelong disabilities and they 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 into adulthood, although severely affected children may have a reduced life expectancy.

Although 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 (oxygen deprivation) during labour and delivery
- The use of certain drugs during pregnancy, such as cocaine
- Excessive alcohol intake during pregnancy
- Genetic factors
- Metabolic problems in the newborn period, such as severe jaundice and hypoglycaemia

Research using blood specimens from babies obtained soon after birth have found associations 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^{2,3,4,5}.

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

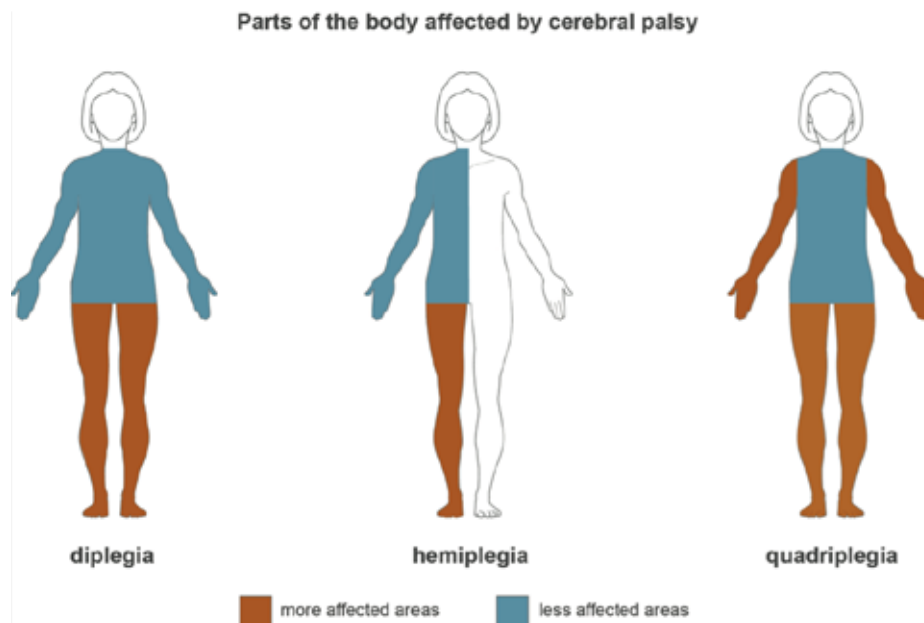
- Near drowning
- Brain hypoxia from any cause
- Some brain tumours
- Head injuries: accidental and non-accidental
- Severe infection involving the brain, such as meningitis or encephalitis
- Cerebrovascular accidents (strokes)
- Non-accidental injuries
- Complications of inborn errors of metabolism

Cerebral Palsy Terminology*

Parts of the Body Affected by Cerebral Palsy

The parts of the body affected by cerebral palsy differ from one person to another. There are specific words used to describe the parts affected:

- Hemiplegia – the leg and arm on one side of the body are affected
- Diplegia – both legs are affected significantly more than the arms. People with diplegia may have some clumsiness with their hand movements
- Quadriplegia – both arms and legs are affected. The muscles of the trunk, face and mouth can also be affected.



Types of Cerebral Palsy

There are three main types of cerebral palsy. Each results from injury to a different part of the brain and its corresponding impact on movement:

Spastic Cerebral Palsy

This is the most common type of cerebral palsy. Spasticity means stiffness or tightness of muscles. The muscles are stiff because the message to the muscles is sent incorrectly through the injured part of the brain. This is the most common type, affecting approximately 77-93% of people with the condition.

When unaffected children perform a movement, some groups of muscles become tighter and some groups of muscles relax. In people with spastic cerebral palsy, both groups of muscles may become tighter. This makes movement difficult or even impossible.

Dyskinetic Cerebral Palsy

This type affects about 2-15% of people with cerebral palsy. There are two forms:

- Athetosis is characterised by uncontrolled, slow, 'stormy', writhing movements;
- Dystonia is characterised by sustained or intermittent muscle contractions causing twisting or repetitive movement.

Ataxic Cerebral Palsy

This is the least common type of cerebral palsy (2-8%) and is characterised by shaky movements. It affects a person's balance and coordination.

*Information has been sourced from the Cerebral Palsy Alliance website. For more information, please visit www.cerebralpalsy.org.au

Funding / Administration / Ethical Approval / Legislative Framework

Funding

The Register is funded by the Women's and Children's Health Network, with additional funding from Novita Children's Services.

Administration

The Register is based at the Women's and Children's Hospital as part of the Women's and Children's Health Network and is located administratively within the Health Informatics, Planning, Performance Outcomes (HIPPO) Unit. Its location enables the Register to draw on the experience and expertise of the Paediatric Rehabilitation Department and Neurology Department of the Women's and Children's Health Network. The Specialist Advisors to the Register are drawn from members of these departments and Novita Children's Services.

Ethics Approval

The establishment of the South Australian Cerebral Palsy Register was approved by the Human Research Ethics Committee of the Women's and Children's Health Network, the North Western Adelaide Health Service and Flinders Medical Centre. Continuing oversight of the ethics of the activities of this state-based Register is carried out by the SA Health, Human Research Ethics Committee.

Legislative framework

The South Australian Cerebral Palsy Register is part of the South Australian Birth Defects Register and operates under the provisions of the South Australian Health Care (Pregnancy Outcome Statistics) Regulations 2008. These Regulations require the notification of all congenital abnormalities diagnosed before the child's fifth birthday.

Part 7 of the *Health Care Act 2008* allows the Register to carry out research into cerebral palsy while maintaining the confidentiality of participants

Aims of the Register

The 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
- Provide information to help 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
- Contribute deidentified data to the Australian Cerebral Palsy Register

How the Register works

Ascertainment

Notifications of children with cerebral palsy come from a variety of sources, including Novita Children's Services, rehabilitation specialists, paediatricians, physiotherapists, neurologists and occupational therapists. The main sources of notification are the Women's and Children's Health Network, Novita Children's Services and Paediatric Rehabilitation Specialists. The Register encourages notifications from all sources, (even when this results in multiple notifications for the same child) as a means of ensuring complete ascertainment of affected children.

All notifications are received by the South Australian Birth Defects Register. Once notified, the Cerebral Palsy Register approaches families through a clinician who is known to them, and who is either 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 with the Register is extended to the family. The managing clinician is also sent a package containing a family information leaflet (Appendix 2) and a "consent to contact" form. Once the clinician has communicated with the family, this 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 to provide detailed information about its aims and functions. Families are asked for written consent for their child to participate in the Register. Those who agree to participate may, at any time, ask to be withdrawn from the Register. Non-participation in the Register will not affect any aspect of the child's medical care and services which may be provided to them. Children included on the Register are given a full clinical assessment at around school 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. Consent is obtained from each family with an affected child 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 to ensure accurate and complete data for each child.

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. Information relating to the perinatal period is also collected.

Data Storage and Confidentiality

The collected data are stored electronically using unique identifier codes to maintain participant confidentiality. All information and participant files are backed up regularly to prevent data loss. 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 (non-progressive) cerebral pathology. The Register also includes cases of cerebral palsy acquired after the neonatal period (after the first month and before 2 years of age).

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) ¹, and more recently, by the updated publication by Smithers-Sheedy et al (2014) ⁶.

Participation in the Australian Cerebral Palsy Register

The Register has been involved in the establishment of the Australian Cerebral Palsy Register (ACPR). Its staff have contributed to the development of the ACPR Agreement and Working Guidelines which have been developed to define the protocols for transferring anonymous information about South Australian children with cerebral palsy to the ACPR as part of a national strategy to monitor the frequency of cerebral palsy and to undertake research into its causes ⁷.

Prevalence of cerebral palsy 1993 – 2010

In South Australia, 676 children with cerebral palsy were born between 1993 and 2010, and had been notified to the Register by 31st December 2015. A comprehensive clinical assessment at around school age has been completed for 482 (95.1%) of the 507 children eligible for assessment (see Table 1). Over this same period, the Register also received 115 notifications of cases born interstate or overseas. These children are invited to participate in the Register if they have a diagnosis of cerebral palsy and are receiving medical treatment in South Australia, but are not included in this report.

Tables 1-8 and Figures 1-6 present data about children with cerebral palsy notified to the South Australian Birth Defects Register.

Group	1993-2005	2006	2007	2008	2009	2010	1993-2010	
	No.	No.	No.	No.	No.	No.	No.	(%)
Assessment completed at 5 years	348	28	33	26	31	16	482	(71.3)
Awaiting assessment	7	0	1	4	4	9	25	(3.7)
Consents not complete	3	3	2	1	4	3	16	(2.4)
Medical reports only	114	8	6	2	2	3	135	(20.0)
Deceased prior to 5 years	15	0	3	0	0	0	18	(2.7)
Total*	487	39	45	33	41	31	676	(100)

**Does not include interstate or overseas births: 74 between 1993-2005, 9 in 2006, 11 in 2007, 9 in 2008, 6 in 2009 and 6 in 2010 (total of 115)*

Research has shown that some of the notified cases will have their initial cerebral palsy diagnosis changed to a non-cerebral palsy diagnosis prior to age five or following assessment at around five years of age⁸. These children are not presented in this report. Minimum and maximum prevalence estimates have been calculated for the years 1993 – 2010 (Table 2). The maximum reflects total ascertained cases and the minimum estimate is based on assessed cases only.

Year of birth	Live births	Ascertained cases	Assessed cases*		Prevalence / 1,000# max / min	
1993-2005	239,680	487	348	(71.5)	2.03	1.45
2006	18,663	39	28	(71.8)	2.09	1.50
2007	19,624	45	33	(73.3)	2.29	1.68
2008	19,819	33	26	(78.8)	1.67	1.31
2009	19,761	41	31	(75.6)	2.07	1.57
2010	19,883	31	16	(51.6)	1.56	0.80
1993-2010	337,430	676	482	(71.3)	2.00	1.43

**Have completed comprehensive clinical assessment at around 5 years of age*
Rate per 1,000 live births. Minimum rate represents assessed cases and maximum rate reflects total ascertained cases

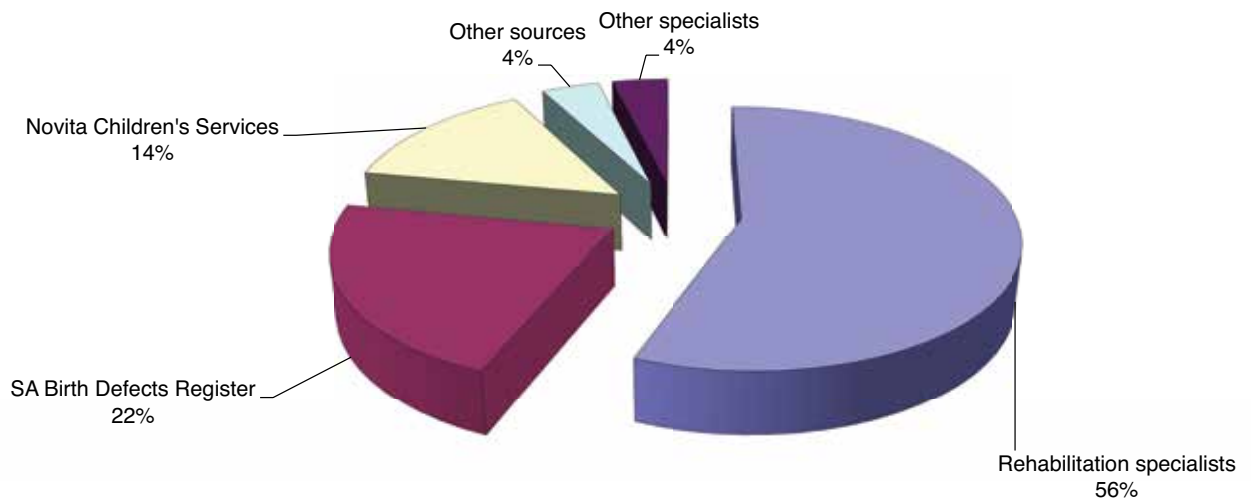
Notifiers to the Register

The sources of notification of children with cerebral palsy born between 1993 and 2010 are shown in Table 3. Over this period, 92% of the notifications came from three main sources, Rehabilitation specialists, the South Australian Birth Defects Register and Novita Children's Services.

Table 3: Notifiers to the Register 1993 – 2010								
Notifier*	1993-2005 No.	2006 No.	2007 No.	2008 No.	2009 No.	2010 No.	1993-2010	
							No.	(%)
Rehabilitation specialists	238	27	35	24	33	22	379	(56.1)
SA Birth Defects Register	116	7	5	6	6	8	148	(21.9)
Novita Children's Services	91	3	1	1	0	0	96	(14.2)
Other sources#	23	0	0	2	2	0	27	(4.0)
Other specialists	19	2	4	0	0	1	26	(3.8)
Total	487	39	45	33	41	31	676	(100)

* The Register encourages multiple notifications
 # Other sources include allied health services such as physiotherapy and occupational therapy

Figure 1: Notifiers to the Register 1993 – 2010



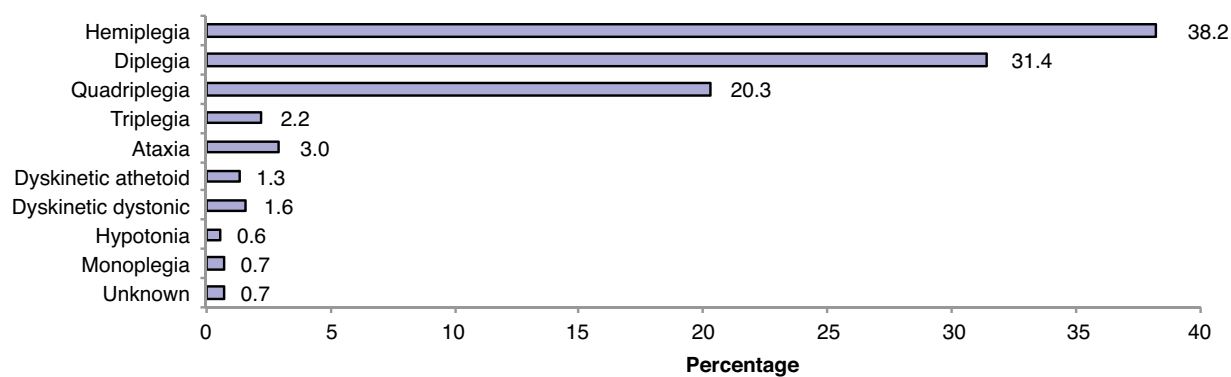
Type of cerebral palsy

The different types of cerebral palsy for children born between 1993 and 2010 are shown in Table 4. The most common forms of cerebral palsy were hemiplegia, diplegia and quadriplegia, accounting for 90% of all cases.

Table 4: Type of cerebral palsy 1993 – 2010								
Type of cerebral palsy	1993-2005 No.	2006 No.	2007 No.	2008 No.	2009 No.	2010 No.	1993-2010	
							No.	(%)
Hemiplegia	171	21	15	15	22	14	258	(38.2)
Diplegia*	162	11	13	8	8	10	212	(31.4)
Quadriplegia#	101	7	12	7	6	4	137	(20.3)
Triplegia	14	0	0	1	0	0	15	(2.2)
Ataxia	14	0	3	0	3	0	20	(3.0)
Dyskinetic athetoid	7	0	0	2	0	2	11	(1.3)
Dyskinetic dystonic	9	0	0	0	0	0	9	(1.6)
Hypotonia	2	0	0	0	1	1	4	(0.6)
Monoplegia	3	0	1	0	1	0	5	(0.7)
Unknown	4	0	1	0	0	0	5	(0.7)
Total	487	39	45	33	41	31	676	(100)

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

Figure 2: Type of cerebral palsy 1993 – 2010

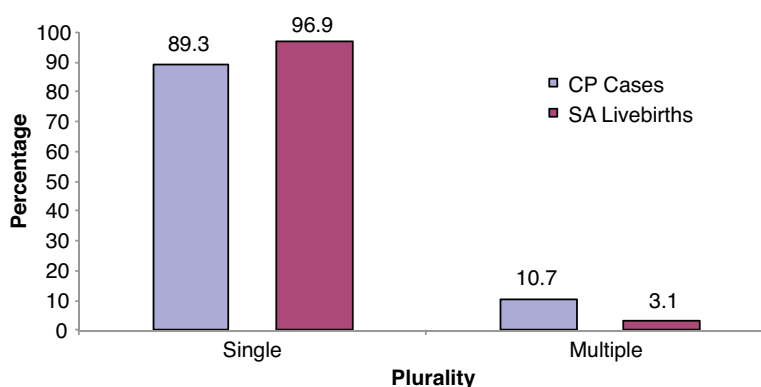


Plurality and sex of child

The distribution of cerebral palsy cases by plurality is shown in Table 5 and Figure 3. The percentage of cerebral palsy cases among multiple births was 10.7% for the period 1993-2010, compared with the South Australian livebirth population, where multiple births accounted for 3.1% of all livebirths for the same period. This demonstrates a strong relationship between cerebral palsy and multiple births.

Plurality	1993-2005 No.	2006 No.	2007 No.	2008 No.	2009 No.	2010 No.	1993-2010	
							No.	(%)
Singleton	436	31	42	31	35	29	604	(89.3)
Multiple	51	8	3	2	6	2	72	(10.7)
Total	487	39	45	33	41	31	676	(100)

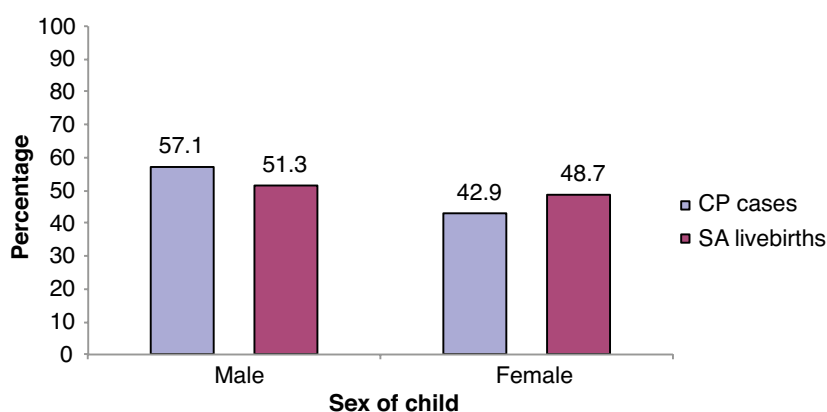
Figure 3: Cerebral palsy by plurality 1993 – 2010



The distribution of cerebral palsy cases by the sex of child is shown in Table 6 and Figure 4. The percentage of males with cerebral palsy was 57.1% for the period 1993-2010, compared with the South Australian livebirth population, where males accounted for 51.3% of all livebirths for the same period.

Sex	1993-2005 No.	2006 No.	2007 No.	2008 No.	2009 No.	2010 No.	1993-2010	
							No.	(%)
Male	273	24	27	20	26	16	386	(57.1)
Female	214	15	18	13	15	15	290	(42.9)
Total	487	39	45	33	41	31	676	(100)

Figure 4: Cerebral palsy by sex 1993 – 2010



Gestational age at birth

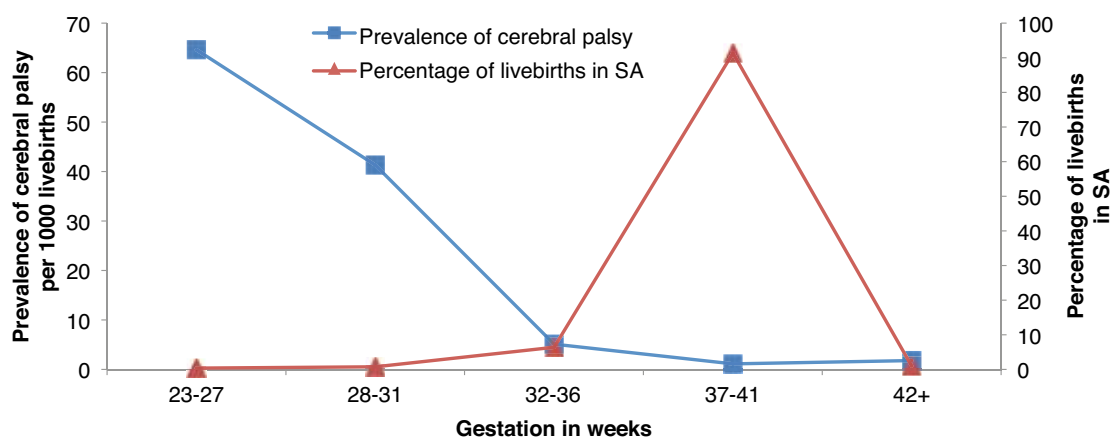
The gestational ages at birth for cases of cerebral palsy born between 1993 and 2010 are shown in Table 7. There were 53.1% of cases born at term (≥ 37 weeks gestation).

The prevalence of cerebral palsy by gestational age at birth 1993 – 2010 is also demonstrated in Table 7 and Figure 5 illustrating the association between cerebral palsy and prematurity (<37 weeks gestation), especially gestations <32 weeks.

Table 7: Cerebral palsy by gestational age at birth 1993 – 2010									
Gestation weeks*	1993-2005 No.	2006 No.	2007 No.	2008 No.	2009 No.	2010 No.	1993-2010		1993-2010 Prevalence#
							No.	(%)	
23 [^] – 27	70	2	7	3	7	3	92	(13.6)	64.7
28 – 31	82	7	7	7	3	7	113	(16.7)	41.3
32 – 36	81	6	5	4	6	10	112	(16.6)	5.1
37 – 41	251	24	25	18	25	10	353	(52.2)	1.1
42+	3	0	1	1	0	1	6	(0.9)	1.8
Total	487	39	45	33	41	31	676	(100)	2.00

* Gestation at birth (best clinical estimate) in weeks, [^] There were no cases below 23 weeks, # Prevalence per 1,000 live births

Figure 5: Prevalence of cerebral palsy by gestational age at birth 1993 – 2010



For full colour graph, please refer to the electronic report on our website: http://www.wch.sa.gov.au/services/az/other/phru/cerebral_palsy.html

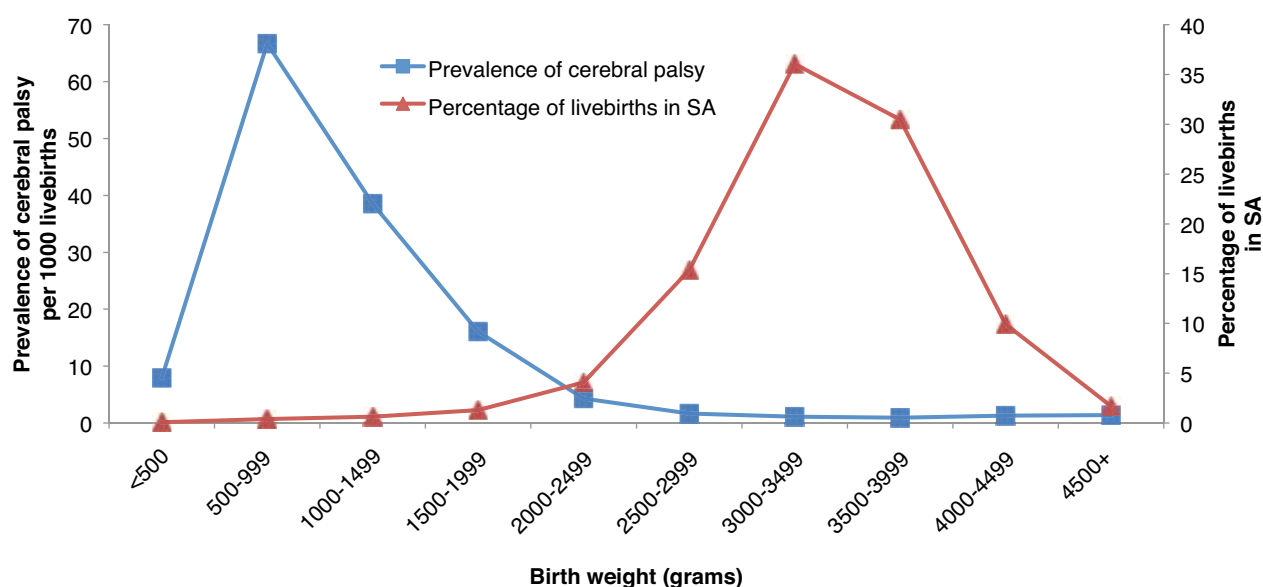
Birth weight

The prevalences of cerebral palsy per 1,000 live births, by birth weight, are provided in Table 8 and Figure 6 for the period 1993 – 2010. They demonstrate a strong relationship between cerebral palsy and low birth weight. As birth weight increases, the prevalence of cerebral palsy decreases, from 66.7 per 1,000 live births at 500 – 999g to 0.9 per 1,000 live births at 3,500 – 3,999g. Due to high mortality in the <500g birth weight group, the prevalence of cerebral palsy appears relatively low at 7.9 per 1,000 live births.

Birth weight range (grams)	1993-2005 No.	2006 No.	2007 No.	2008 No.	2009 No.	2010 No.	1993-2010		1993-2010 Prevalence#
							No.	(%)	
< 500	2	0	0	0	0	0	2	(0.3)	7.9
500 – 999	68	2	7	5	6	4	92	(13.6)	66.7
1,000 – 1,499	61	5	7	2	4	3	82	(12.1)	38.6
1,500 – 1,999	50	4	2	5	4	6	71	(10.5)	16.1
2,000 – 2,499	40	4	3	5	2	5	59	(8.7)	4.3
2,500 – 2,999	66	5	4	4	6	2	87	(12.9)	1.7
3,000 – 3,499	93	8	13	5	10	6	135	(20.0)	1.1
3,500 – 3,999	71	5	5	5	6	4	96	(14.2)	0.9
4,000 – 4,499	30	6	3	1	3	1	44	(6.5)	1.3
4,500 – 4,999	6	0	1	1	0	0	8	(1.2)	1.4
Total	487	39	45	33	41	31	676	(100)	2.00

Prevalence per 1,000 live births

Figure 6: Prevalence of cerebral palsy by birth weight 1993 – 2010



For full colour graph, please refer to the electronic report on our website: http://www.wch.sa.gov.au/services/az/other/phru/cerebral_palsy.html

Level of motor function

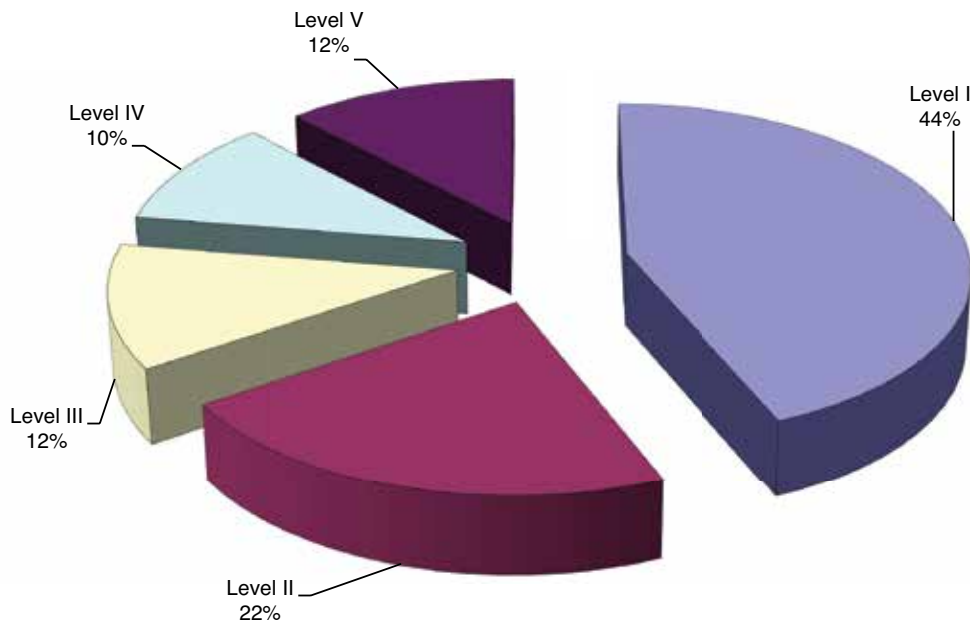
Tables 9-14 and Figures 7-9 present additional data collected at the 5 year assessment. At 31st December 2015, 482 (95.1%) of the 507 children who were eligible to be assessed, had completed their comprehensive clinical assessment at around five years of age. For various reasons, there were 169 cases that were not able to complete a clinical assessment (18 had died before the age of five years, 36 did not want to participate in the register, and 115 were not able to be contacted).

Table 9 and Figure 7 show the level of motor function, using the Gross Motor Function Classification System (GMFCS)⁹ for children with cerebral palsy born 1993 – 2010. The majority of children had less restricted motor function and were assessed at Levels I and II i.e. walking without restriction (44%) and walking without assistive devices (22%) respectively, while 34% were more severely affected in their motor function (assessed at Levels III – V), with limitations or severe limitations to self-mobility. Definitions of motor function levels appear in Appendix 1.

Table 9: Gross Motor Function Classification 1993 – 2010								
Level of function [^]	1993-2005 No.	2006 No.	2007 No.	2008 No.	2009 No.	2010 No.	1993-2010	
							No.	(%)
Level I	166	16	6	6	8	8	210	(43.6)
Level II	70	3	11	5	10	6	105	(21.8)
Level III	29	2	8	10	7	1	57	(11.8)
Level IV	36	4	6	1	3	0	50	(10.4)
Level V	46	3	2	4	2	1	58	(12.0)
Unknown	1	0	0	0	1	0	2	(0.4)
Total	348	28	33	26	31	16	482	(100)

[^] Definitions of the Gross Motor Function Classification System (GMFCS) appear in Appendix 1

Figure 7: Gross Motor Function Classification 1993 – 2010



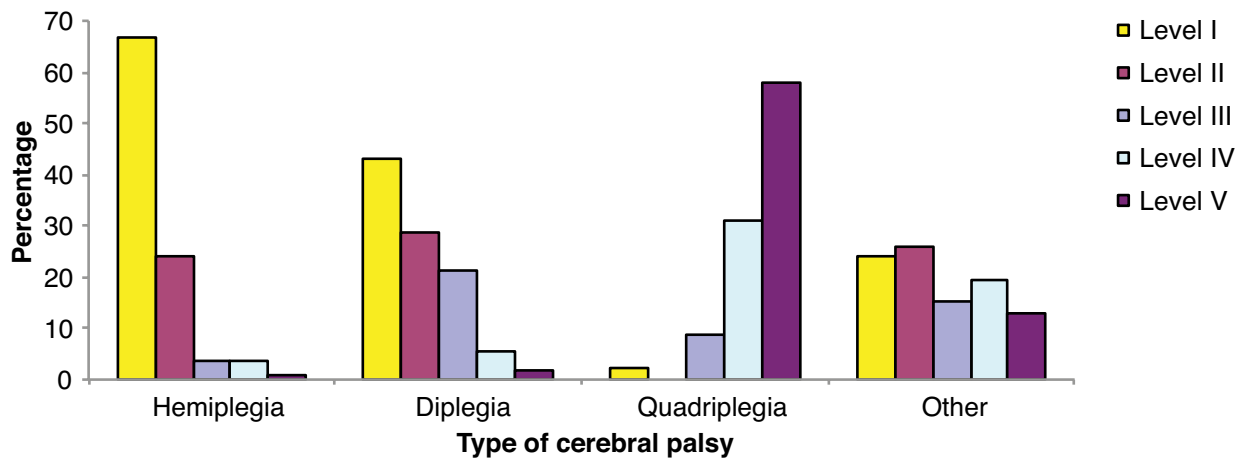
Level of motor function by type of cerebral palsy

Table 10 and Figure 8 show the level of motor function using the gross motor function classification system (GMFCS) by type of cerebral palsy for children born 1993 – 2010. The majority of children with hemiplegia had less restricted motor function Levels I and II (91%). In comparison, the majority of children with quadriplegia had severe limitations to self-mobility and were assessed at Levels IV and V (89%). Definitions of motor function levels appear in Appendix 1.

Table 10: Level of motor function by type of cerebral palsy 1993 – 2010						
Type of cerebral palsy	Level of Function [^]					Total
	Level I (%)	Level II (%)	Level III (%)	Level IV (%)	Level V (%)	
Hemiplegia	124 (66.7)	45 (24.2)	7 (3.8)	7 (3.8)	2 (1.1)	186
Diplegia*	72 (42.9)	48 (28.6)	36 (21.4)	9 (5.4)	3 (1.8)	168
Quadriplegia [#]	2 (2.5)	0 (0.0)	7 (8.6)	25 (30.9)	47 (58.0)	81
Other	11 (23.9)	12 (26.1)	7 (15.2)	9 (19.6)	6 (13.0)	46
Unknown	1 (100.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1
Total	210 (43.6)	105.0 (21.8)	57.0 (11.8)	50.0 (10.4)	58.0 (12.0)	482

* Spasticity in four limbs: Lower limbs greater than upper limbs
[#] Spasticity in four limbs: Upper limbs greater than or equal to lower limbs
[^] Definitions of the Gross Motor Function Classification System (GMFCS) appear in Appendix 1

Figure 8: Level of motor function[^] by type of cerebral palsy 1993 – 2010



[^] Definitions of the Gross Motor Function Classification System (GMFCS) appear in Appendix 1

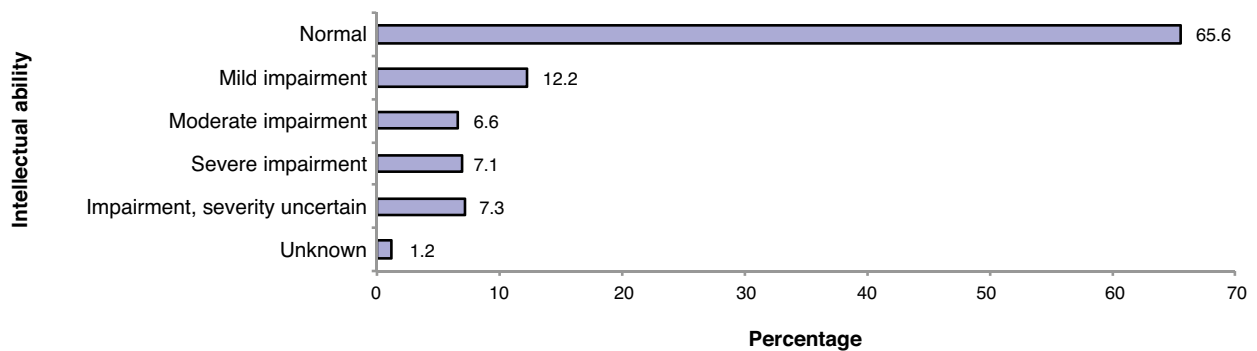
Co-morbidities

Table 11 and Figure 9 illustrate the level of intellectual ability for children with cerebral palsy born 1993 – 2010. In 2009, SA adopted the categories used by the Australian Cerebral Palsy Register to illustrate intellectual ability. These show that 66% of children with cerebral palsy were considered to have normal intellectual ability, 12% had mild intellectual impairment, and 14% had moderate to severe intellectual impairment.

Table 11: Intellectual ability 1993 – 2010								
Intellectual ability #	1993-2005 No.	2006 No.	2007 No.	2008 No.	2009 No.	2010 No.	1993-2010	
							No.	(%)
Normal	228	20	18	18	19	13	316	(65.6)
Mild Impairment	44	1	6	3	5	0	59	(12.2)
Moderate Impairment	23	3	2	0	2	2	32	(6.6)
Severe Impairment	31	0	1	2	0	0	34	(7.1)
Impairment: severity uncertain	17	4	5	3	5	1	35	(7.3)
Unknown	5	0	1	0	0	0	6	(1.2)
Total	348	28	33	26	31	16	482	(100)

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

Figure 9: Intellectual ability# 1993 – 2010



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

Table 12 shows the frequency of visual impairment in children with cerebral palsy born 1993 – 2010. Normal vision was reported for 60% of children and 37% had impaired vision.

Table 12: Vision 1993 – 2010								
Vision	1993-2005 No.	2006 No.	2007 No.	2008 No.	2009 No.	2010 No.	1993-2010	
							No.	(%)
Normal	192	21	23	18	22	13	289	(60.0)
Impaired*	141	7	10	8	8	3	177	(36.7)
Unknown	15	0	0	0	1	0	16	(3.3)
Total	348	28	33	26	31	16	482	(100)

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

Table 13 shows the frequency of hearing impairment in children with cerebral palsy born 1993 – 2010. Normal hearing was reported for 92% of children and 6% had impaired hearing or bilateral deafness.

Table 13: Hearing 1993 – 2010								
Hearing	1993-2005 No.	2006 No.	2007 No.	2008 No.	2009 No.	2010 No.	1993-2010	
							No.	(%)
Normal	319	26	32	24	29	14	444	(92.1)
Impaired*	16	1	1	2	1	0	21	(4.4)
Bilateral deafness	6	1	0	0	0	1	8	(1.7)
Unknown	7	0	0	0	1	1	9	(1.9)
Total	348	28	33	26	31	16	482	(100)

* Impaired hearing includes: sensorineural and/or conductive hearing loss determined by audiology

The frequency of epilepsy in children with cerebral palsy born 1993 – 2010 is shown in Table 14. A diagnosis of epilepsy was reported for 27% of children, compared with 71% who had never been diagnosed with epilepsy.

Table 14: Epilepsy 1993 – 2010								
Epilepsy	1993-2005 No.	2006 No.	2007 No.	2008 No.	2009 No.	2010 No.	1993-2010	
							No.	(%)
No epilepsy	247	19	22	21	19	12	340	(70.5)
epilepsy	88	9	11	5	12	4	129	(26.8)
Unknown	13	0	0	0	0	0	13	(2.7)
Total	348	28	33	26	31	16	482	(100)

The frequency of speech impairment in children with cerebral palsy born 1993 – 2010 is shown in Table 15. Normal speech was reported for 44% of children, and the remaining 55% had either impaired speech or were non-verbal.

Speech	1993-2005 No.	2006 No.	2007 No.	2008 No.	2009 No.	2010 No.	1993-2010	
							No.	(%)
Normal	159	16	9	12	9	9	214	(44.4)
Impaired*	143	8	17	10	18	5	201	(41.7)
Non verbal	42	4	7	4	3	2	62	(12.9)
Unknown	4	0	0	0	1	0	5	(1.0)
Total	348	28	33	26	31	16	482	(100)

* Impaired speech ranges from "some problems when excited" to "only understood by family members"

Table 16 presents the types of cerebral palsy with associated co-morbidities of hearing, vision, epilepsy and intellectual impairment. Some differences can be seen, for example between quadriplegic and diplegic types of cerebral palsy, especially with respect to vision, epilepsy and intellectual impairment. 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 impairment is defined as mild to severe impairment.

Type of cerebral palsy	Total in category	Hearing impairment		Vision impairment		Epilepsy		Intellectual impairment*	
		No.	(%)	No.	(%)	No.	(%)	No.	(%)
Hemiplegia	186	10	(5.4)	51	(27.4)	45	(24.2)	42	(22.6)
Diplegia	168	5	(3.0)	53	(31.5)	22	(13.1)	36	(21.4)
Quadriplegia	81	11	(13.6)	55	(67.9)	48	(59.3)	62	(76.5)
Triplegia	14	0	(0.0)	5	(35.7)	3	(21.4)	4	(28.6)
Ataxia	13	3	(23.1)	6	(46.2)	3	(23.1)	8	(61.5)
Dyskinetic athetoid	6	0	(0.0)	1	(16.7)	2	(33.3)	1	(16.7)
Dyskinetic dystonic	9	0	(0.0)	5	(55.6)	4	(44.4)	6	(66.7)
Hypotonia	1	0	(0.0)	0	(0.0)	1	(100.0)	0	(0.0)
Monoplegia	3	0	(0.0)	0	(0.0)	0	(0.0)	1	(33.3)
Unspecified type	1	0	(0.0)	1	(100.0)	1	(100.0)	0	(0.0)
Total (% of total)#	482	29	(6.0)	177	(36.7)	129	(26.8)	160	(33.2)

* Children considered to have mild to severe intellectual impairment,
Some of the children have multiple co-morbidities, therefore the totals do not add up to 100%

Provisional data for children born 2011 – 2015

The South Australian Cerebral Palsy Register is now publishing provisional data for children who were born between 1st January 2011 and 31st December 2015, and who have been notified to the Register (Table 17).

Notifications of cases are continuing for those children born between 2011 and 2015, as cerebral palsy is not immediately apparent at birth. Most, however, have been diagnosed by age five years. The numbers for these years will be updated as the Register is notified of additional children diagnosed with cerebral palsy.

Research has also shown that some of the notified cases will have their initial cerebral palsy diagnosis changed to a non-cerebral palsy diagnosis following assessment or review at around five years of age⁸. The majority of children represented in the table below have not yet reached the age where assessments are offered, and it is inevitable that some of these children will have their initial diagnosis of cerebral palsy changed in the coming years.

For these reasons, we are presenting these provisional data separately to the results for children born between 1993 and 2010.

Table 17: Provisional data for SA children with cerebral palsy 2011 – 2015							
Group	2011 No.	2012 No.	2013 No.	2014 No.	2015 [#] No.	2011-2015	
						No.	(%)
Assessment completed at 5 years	4	0	0	0	0	4	(5.3)
Awaiting assessment	16	10	13	0	0	39	(52.0)
Consents not complete	9	9	7	3	1	29	(38.7)
Medical reports only	2	0	0	0	1	3	(4.0)
Deceased prior to 5 years	0	0	0	0	0	0	(0.0)
Total*	31	19	20	3	2	75	(100)

[#] Most cases of cerebral palsy are diagnosed after one year of age.
^{*} Does not include interstate or overseas births: 3 in 2011, 4 in 2012, 1 in 2013, zero in 2014 and 2015 (total of 8)

References

1. 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: 520-527.
2. Nelson KB, Dambrosia JM, Grether JK, Phillips TM. Neonatal cytokines and coagulation factors in children with cerebral palsy. *Annals of Neurology* 1998; 44: 665-675.
3. 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. *American Journal of Obstetrics and Gynecology* 2005; 193: 1437 e1-e12.
4. 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. *American Journal of Obstetrics and Gynecology* 2006; 194: 674 e1-e11.
5. 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.
6. Smithers-Sheedy H, Badawi N, Blair E, Cans C, Himmelmann K, Krageloh-Mann I, McIntyre S, Slee J, Uldall P, Watson L, Wilson M. What constitutes cerebral palsy in the twenty-first century? *Developmental Medicine and Child Neurology* 2014; 56(4): 323-328.
7. Australian Cerebral Palsy Register. Report of the Australian Cerebral Palsy Register, Birth Years 1993-2006. Sydney: Cerebral Palsy Alliance Research Institute, 2013.
8. Zarrinkalam R, Russo RN, Gibson CS, van Essen PB, Peek AK, Haan EA. Cerebral palsy or not cerebral palsy? A review of cerebral palsy diagnoses in a cerebral palsy Register. *Pediatric Neurology* 2010; 42(3): 177-180.
9. Palisano R, 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. *Developmental Medicine and Child Neurology* 1997; 39: 214-223.

Publications and Presentations

The South Australian Cerebral Palsy Register has been involved in many research projects since it was established. For a full listing of publications and presentations utilising data from the SA Cerebral Palsy Register, please refer to our website: http://www.wch.sa.gov.au/services/az/other/phru/cerebral_palsy.html

Appendix 1

Gross Motor Function Classification System (GMFCS) in cerebral palsy ⁹

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 age 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 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 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 the 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 impairment limits 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.

Distinction 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)⁹.

Appendix 2

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 only a small fraction of cases stem from 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.

The South Australian Cerebral Palsy Register was established in 1998 with support from the Crippled Children's Association (now Novita Children's Services) and the Women's and Children's Hospital. It is located at the Women's and Children's Hospital in the Health Informatics, Planning, Performance Outcomes (HIPPO) Unit and is funded by Women's and Children's Health Network, with support from Novita Children's Services. It is a collaboration between the Register, the Paediatric Rehabilitation Department (Women's and Children's Health Network) and Novita Children's Services.

The Register contributes de-identified data to the Australian Cerebral Palsy Register as part of a national strategy to monitor the frequency of cerebral palsy and to undertake research into its causes.

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?

When your child is around school age he/she will receive a free, comprehensive medical assessment by a paediatric rehabilitation specialist. This assessment can take place at the Women's and Children's Hospital or Novita Children's Services during a scheduled appointment with one of the doctors from the Paediatric Rehabilitation Department. Information gained by the specialist may be used to make recommendations to your child's doctor about services or treatment. You may choose to receive newsletters, a copy of the Annual Report and other information which may be of interest to you, including information about current research.

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 ways of caring for children with cerebral palsy;
- 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. The paediatric rehabilitation specialists who work with the Register are A/Prof Ray Russo, Dr James Rice, Dr Andrew Tidemann, Dr Phil Egan, Dr Deepa Jeyaseelan, Dr Nick Ricci and Dr Rosa Zarrinkalam. One of these specialists will conduct your child's medical assessment.

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 the Register will use this information, and any such use must first be approved by a Human Research Ethics Committee. The Register provides anonymous information about South Australian children with cerebral palsy to the Australian Cerebral Palsy Register for research purposes only. 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 Human Research Ethics Committees of the Women's and Children's Health Network, 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. Feel free to contact the Register Officer and ask any questions you may have at that time.

If you decide that you would like your child to be included then please sign and return the Consent Form in the prepaid envelope provided, *(if you decide not to participate please let the Register Officer know this by return mail so we know not to contact you in future).*

When your child is around five years of age, a paediatric rehabilitation specialist will conduct a one-off medical assessment. This will usually be conducted at your local Regional Office of Novita Children's Services. (We also have rural clinics in key central areas. It may be possible to make other arrangements for country families and those who would find it difficult to get to Adelaide).

The medical assessment will be conducted free of charge. You will receive no payment for your participation.

Although paediatric rehabilitation specialists working with the Cerebral Palsy Register will conduct the medical assessment, your child will remain in the care of his/her 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. 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.

If you have any further questions please feel free to contact the Register Officer, South Australian Cerebral Palsy Register, on (08) 8161 7242 during office hours. E-mail cpregister@sa.gov.au




For more information

South Australian Cerebral Palsy Register

Health Informatics, Planning, Performance Outcomes (HIPPO) Unit

Women's and Children's Health Network
2nd Floor Michell Building
72 King William Road
North Adelaide, South Australia 5006
Telephone: (08) 8161 7368
Email: sabdr@sa.gov.au

 If you do not speak English, request an interpreter from SA Health and the department will make every effort to provide you with an interpreter in your language.



www.ausgoal.gov.au/creative-commons

