2007 Annual Report

of

The South Australian Cerebral Palsy Register

(part of The South Australian Birth Defects Register)

Children born 1993 to 2002 with cerebral palsy notified to the Register by 31st December 2007

May 2008

The South Australian Cerebral Palsy Register

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Register Staff

Professor Eric Haan	*Clinical Geneticist, Head, SA Clinical Genetics Service*
A/Professor Annabelle Chan	*Public Health Physician*
Mrs Phillipa van Essen	*Manager, SA Birth Defects Register (part-time)*
Dr Catherine Gibson	*Manager, SA Birth Defects Register (part-time)*
Ms Ann Peek	*Register Officer, Cerebral Palsy Register*
Ms Heather Scott	*Register Officer, SA Birth Defects Register*

Specialist Advisers to the Register

Dr Andrew Tidemann	*Paediatric Rehabilitation Specialist*
Dr Deirdre White	*Developmental Paediatrician*
Ms Terry Lyons	*Acting Director, Client Programs, Novita Children's Service*
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A/Professor Peter Marshall	*Neonatal Paediatrician, Neonatal Follow-up Program, Flinders Medical Centre*

Register Management Group

Professor Eric Haan	*Representing the SA Birth Defects Register*
A/Professor Annabelle Chan	*Representing SA Department of Health, Epidemiology Branch*
Dr Ray Russo	*Paediatric Rehabilitation Specialist*
Mrs Phillipa van Essen	*Manager, SA Birth Defects Register (part-time)*
Dr Catherine Gibson	*Manager, SA Birth Defects Register (part-time)*
Ms Ann Peek	*Register Officer, Cerebral Palsy Register*
Ms Heather Scott	*Register Officer, SA Birth Defects Register*

Collaborating Organisations

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

Funding

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The South Australian Cerebral Palsy Register – Annual Report 2007

Contents

Tables, Figures and Appendices

Tables & Figures

All notified children with cerebral palsy born in South Australia

Children with cerebral palsy born in South Australia and assessed at five years of age

Appendices

Foreword

A new landmark for cerebral palsy (CP) research was reached in 2007 when Professor Fiona Stanley from the Telethon Institute for Child Health Research in Perth launched the Australian Cerebral Palsy Register (ACPR). The ACPR is a national database, committed to cerebral palsy research, with contributions from each State and Territory CP Register in Australia. The ACPR exists to reduce the incidence of CP and significantly enhance the quality of life of those living with CP. Amalgamation of data from all Australian States has created the largest cerebral palsy register in the world. This large database provides researchers with the opportunity to answer research questions that could not have been considered before using smaller datasets. This exciting development brings together Australia's finest cerebral palsy researchers from State and Territory CP Register teams, to pool their research experience and knowledge, and to collaborate on future research projects using the combined data set. This new collaboration will contribute to making a difference to lives of people with CP, their families and future generations. It will assist service providers to plan resource allocation and assist researchers in answering the questions that families, children and adults ask – *What are the causes of cerebral palsy? Can it be prevented?* and *What are the most effective interventions for improving quality of life?*

It is with much gratitude that I thank the South Australian Cerebral Palsy Register team for their contribution to making an Australian register possible. The spirit of partnership and sharing of information and expertise shown by the SA register has been an inspiration to other Australian states that have taken up the opportunity of developing new state CP Registers that contribute to the Australian register. This great achievement is due to the vision and innovation of Australian researchers and the generosity of the long-established CP Registers such as South Australia, Western Australia and Victoria. The South Australian CP Register team has a long and impressive history of making ground-breaking contributions to our understanding of cerebral palsy. Along with other long-established CP Registers, the work of the team at the SA CP Register has changed our understanding of the origins of cerebral palsy and contributed to innovations in management for those living with the condition.

Australian Cerebral Palsy Register Team, Annual meeting, Sydney 2008

Congratulations to the South Australian CP Register team for their on-going work with both the SA CP Register and their contributions to the Australian Cerebral Palsy Register.

Iona Novak
Head of Research
Cerebral Palsy Institute
Custodian of the Australian Cerebral Palsy Register
A division of The Spastic Centre

South Australian Cerebral Palsy Register Staff

South Australian Cerebral Palsy Register Staff

Left to Right: Mrs Phillipa van Essen, Dr Catherine Gibson, Professor Eric Haan, A/Professor Annabelle Chan and Ms Ann Peek

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 18,644 live births per year (1993-2002).

This report presents information for children with cerebral palsy born in the years 1993-2002.

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 rehabilitation specialists, Novita Children's Services, 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 1993-2002, 378 children with cerebral palsy were ascertained. At 31st December 2007, 72% 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 1993-2002 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 1993–2002 the minimum rate of cerebral palsy was 1.46 per 1,000 live births, and the maximum rate of cerebral palsy was 2.03 per 1,000 live births.

Paediatric rehabilitation specialists notified 45% of cases, Novita Children's Services 23%, the South Australian Birth Defects Register 22%, other sources 6% and other specialists 4%.

Hemiplegia (34%) and diplegia (33%) were the most common forms of cerebral palsy, followed by quadriplegia (22%), triplegia (4%) and ataxia (3%). Dyskinetic athetoid (2%), monoplegia, hypotonia and dyskinetic dystonic (<1.5%) were less common forms of the disorder. In 1% of cases, the type of cerebral palsy was unknown.

49.7% of affected children were born at term (≥37 weeks) and 50.3% were born prematurely (<37 weeks).

The association between the risk of cerebral palsy and prematurity is shown by a prevalence of 80.6 cases per 1,000 live births at 23-27 weeks gestation compared to 1.1 cases per 1,000 live births at term (≥37 weeks).

53% of affected children had a birth weight ≥2,500 grams, 19% weighed 1,500-2,499 grams, 13% weighed 1,000-1,499 grams and 16% weighed <1,000 grams.

The association between the risk of cerebral palsy and low birth weight is shown by a prevalence of 75.2 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.

Of the 273 children assessed, 68% had relatively mild cerebral palsy (gross motor function Levels I and II) while 31% had more severely affected gross motor function (Levels III–V) and in 1% of cases the level of motor function was unknown.

31% of the assessed children born between 1993 and 2002 had impaired intellectual ability (mild to profound disability), 39% had impaired vision and 13% had impaired hearing.

Thanks to Notifiers / Acknowledgments

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 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, Dr Phil Egan and Dr James Rice.

We acknowledge the ongoing assistance of the staff of the Medical Records Departments 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

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 Paediatric Rehabilitation Service 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.

What is Cerebral Palsy?

Cerebral palsy is a term of convenience applied to a group of motor disorders of central origin defined by a clinical description [1]. 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 1993-2002. 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 [2, 3,4 5].

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.

Funding / Administration / Ethical approval / Legislative framework

Funding
The Register is funded by the Children, Youth and Women's Health Service, with additional funding from Novita Children's Services (formerly the Crippled Children's Association).

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 the Register to draw on the experience and expertise of the Paediatric Rehabilitation Service and Neurology Department 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.

Aims of the Register

- 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.

How the Register works

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 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 functions. 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 around 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 also collects cases of cerebral palsy acquired after the neonatal period (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) [1].

Participation in the Australian Cerebral Palsy Register

The register has been involved in the establishment of the Australian Cerebral Palsy Register (ACPR). We have contributed to the development of the Australian Cerebral Palsy Register Agreement and Working Guidelines which have been developed to set out the methods and parameters required to facilitate the transfer of 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.

Register activities 2007

During 2007, 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 (involved in blood clotting, inflammation and defence against infection) 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.
- Attended the launch of the Australian Cerebral Palsy Register (ACPR) in Sydney on the 31st July 2007.
- Collaborated with staff from the Paediatric Rehabilitation Service of the Children, Youth and Women's Health Service on a study investigating notified cases of cerebral palsy who were found subsequently not to have the disorder at or before the Register's five year clinical review.
- Collaborated with staff from the Paediatric Rehabilitation Service of the Children, Youth and Women's Health Service on a study examining motor profiles and associated health and developmental status of children with bilateral limb involvement on the SA CP Register.
- Worked on a project reviewing what has been learned from the 5 year clinical assessments from 1993 to 1998.
- Contributed to the development of the Australian Cerebral Palsy Register (ACPR) Agreement and Working Guidelines Document. This document has been developed to set out the parameters for the national CP Register.

Prevalence of cerebral palsy 1993 - 2002

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 - 2002

Group	1993-1997	1998	1999	2000	2001	2002	1993-2002	
	No.	No	No	No.	No.	No.	No.	(%)
Assessment completed at 5 years	175	33	19	24	14	8	273	(72.2)
Awaiting assessment	3	-	2	4	2	5	16	(4.2)
Consents not completed	3	2	2	6	5	3	21	(5.6)
Medical reports only	32	6	8	5	4	1	56	(14.8)
Deceased prior to 5 years	6	3	-	1	1	1	12	(3.2)
Total*	**219**	**44**	**31**	**40**	**26**	**18**	**378**	**(100)**

*Does not include interstate or overseas births:- two in 1993, five in 1994, six in 1995, six in 1996, five in 1997, six in 1998, four in 1999, two in 2000, four in 2001 and two in 2002 (total of 42).

Three hundred and seventy eight children, born in South Australia (SA) in 1993 – 2002, had been notified to the Register by 31st December 2007. Over this same period, the Register also received 42 notifications of cases born outside SA. A comprehensive clinical assessment at the age of five years has been completed for 273 (72%) of the 378 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 – 2002 (Table 2). The minimum rate represents confirmed cases and the maximum reflects total ascertained cases.

Table 2

Cerebral palsy ascertainment and prevalence 1993-2002

Year of birth	Live births	Ascertained cases	Confirmed cases*		Rate / 1,000# min	/ max
1993 -1997	96,484	219	175	(80%)	1.81	2.27
1998	18,612	44	33	(75%)	1.77	2.36
1999	18,398	31	19	(61%)	1.03	1.68
2000	17,759	40	24	(60%)	1.35	2.25
2001	17,570	26	14	(54%)	0.8	1.48
2002	17,616	18	8	(44%)	0.45	1.02
1993-2002	**186,439**	**378**	**273**	**(72%)**	**1.46**	**2.03**

*Have completed comprehensive clinical assessment at around 5 years of age.
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 2002 are shown in Table 3. Over this period, 90.3% of the notifications came from three main sources, Rehabilitation specialists, Novita Children's Services and the South Australian Birth Defects Register.

Table 3

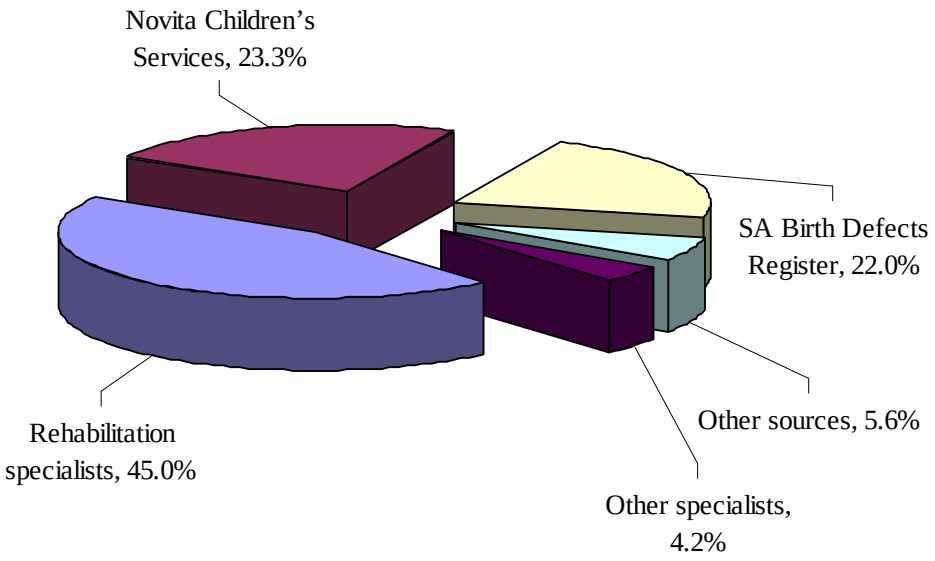
Notifiers to the Register 1993-2002

Notifier*	**1993-1997**	**1998**	**1999**	**2000**	**2001**	**2002**	**1993-2002**	
	No.	**No.**	**No.**	**No.**	**No.**	**No.**	**No.**	**(%)**
Rehabilitation specialists	82	26	13	26	12	11	170	(45.0)
Novita Children's Services	83	5	-	-	-	-	88	(23.3)
SA Birth Defects Register	33	12	14	11	10	3	83	(22.0)
Other sources#	12	1	1	1	3	3	21	(5.6)
Other specialists	9	-	3	2	1	1	16	(4.2)
Total	**219**	**44**	**31**	**40**	**26**	**18**	**378**	**(100)**

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

Figure 1

Notifiers to the Register 1993-2002



Type of cerebral palsy

The different types of cerebral palsy for children born in SA between 1993 and 2002 are shown in Table 4. The most common forms of cerebral palsy were hemiplegia, diplegia and quadriplegia, accounting for 89.5% of all cases.

Table 4

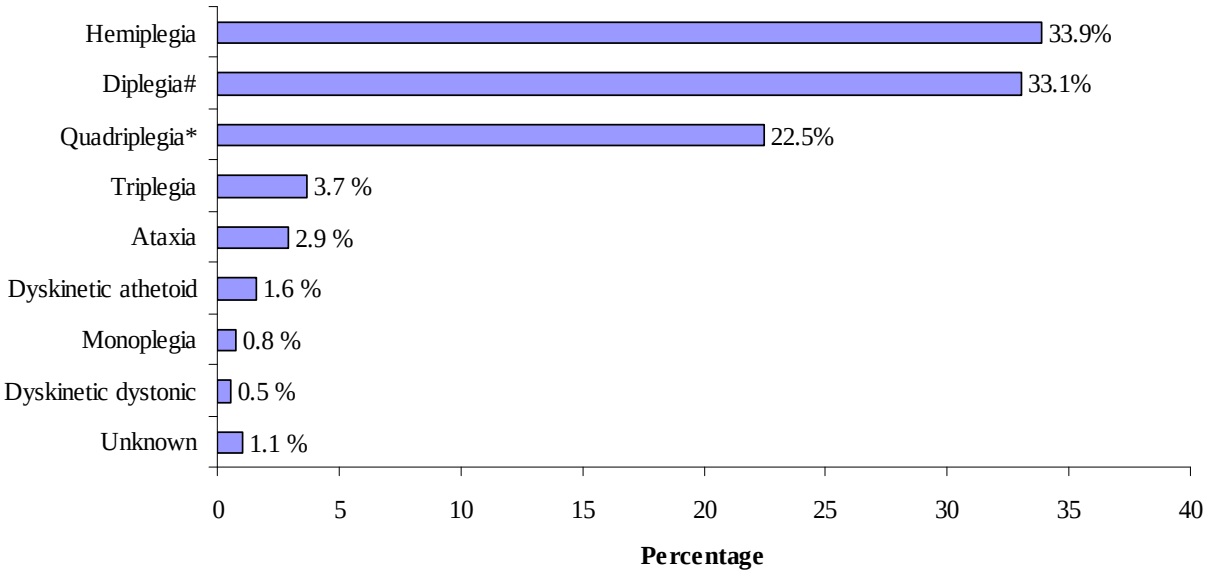
Type of cerebral palsy 1993-2002

Type of cerebral palsy	1993-1997	1998	1999	2000	2001	2002	1993-2002	
	No.	No.	No.	No.	No.	No.	No.	(%)
Hemiplegia	73	12	11	16	8	8	128	(33.9)
Diplegia[#]	77	15	10	12	9	2	125	(33.1)
Quadriplegia[*]	41	11	9	9	9	6	85	(22.5)
Triplegia	13	-	-	-	-	1	14	(3.7)
Ataxia	4	4	1	2	-	-	11	(2.9)
Dyskinetic athetoid	6	-	-	-	-	-	6	(1.6)
Monoplegia	-	2	-	-	-	1	3	(0.8)
Dyskinetic dystonic	1	-	-	1	-	-	2	(0.5)
Unknown	4	-	-	-	-	-	4	(1.1)
Total	**219**	**44**	**31**	**40**	**26**	**18**	**378**	**(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 1993-2002



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

Gestational age at birth

The gestational ages at birth for cases of cerebral palsy born in SA between 1993 and 2002 are shown in Table 5. There were 49.7% of cases born at term (≥37 weeks).

The rate of cerebral palsy by gestational age at birth 1993-2002 is also demonstrated in Table 5 and Figure 3 illustrating the association between cerebral palsy and prematurity (<37 weeks), especially gestations <32 weeks.

Table 5

Cerebral palsy by gestational age at birth 1993-2002

Gestation*	1993 -1997	1998	1999	2000	2001	2002	1993-2002		1993-2002
Weeks	No.	No.	No.	No.	No.	No.	No.	(%)	Rate#
23^ - 27	34	13	4	3	3	0	57	(15.1)	80.6
28 - 31	40	7	8	9	3	1	68	(18.0)	45.2
32 - 36	34	8	6	9	5	3	65	(17.2)	5.7
37 - 41	109	16	13	19	15	14	186	(49.2)	1.1
42+	2	0	0	0	0	0	2	(0.5)	0.8
Total	**219**	**44**	**31**	**40**	**26**	**18**	**378**	**(100)**	2.0

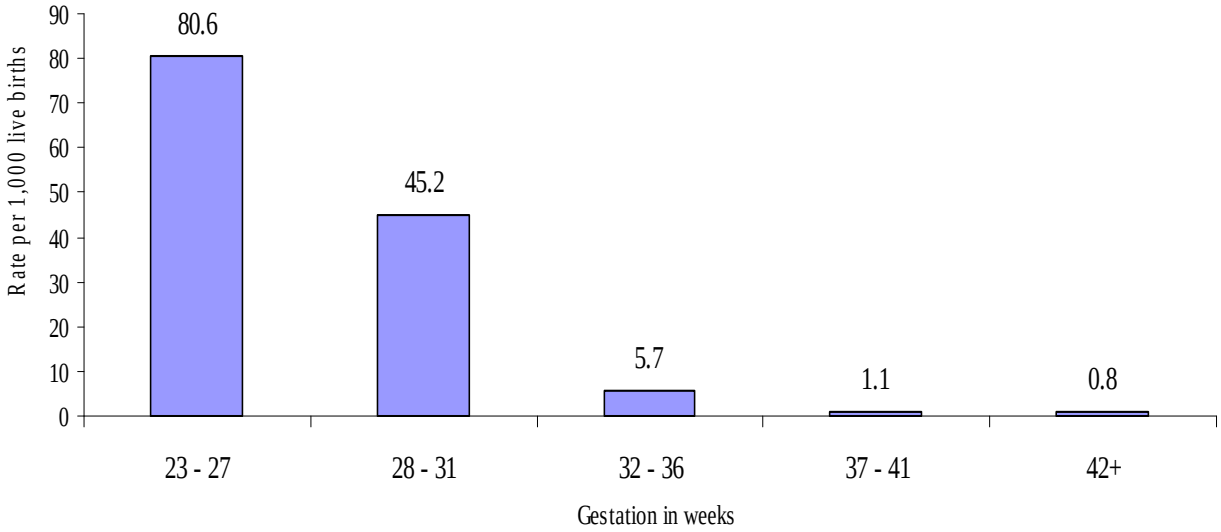
*Gestation at birth (best clinical estimate) in weeks

^There were no cases below 23 weeks

Rate per 1,000 live births

Figure 3

Cerebral palsy by gestational age at birth 1993-2002



Birth weight

The rates of cerebral palsy per 1,000 live births, by birth weight, are provided in Table 6 and Figure 4 for the period 1993-2002. They demonstrate a strong relationship between cerebral palsy and low birth weight. As birth weight increases, the rate of cerebral palsy decreases, from 75.2 per 1,000 live births at 500 – 999g to 0.8 per 1,000 live births at 3,500 – 3,999g. Due to the high mortality rates in the <500g birth weight group the rate of cerebral palsy appears relatively low at 7.9%.

Table 6

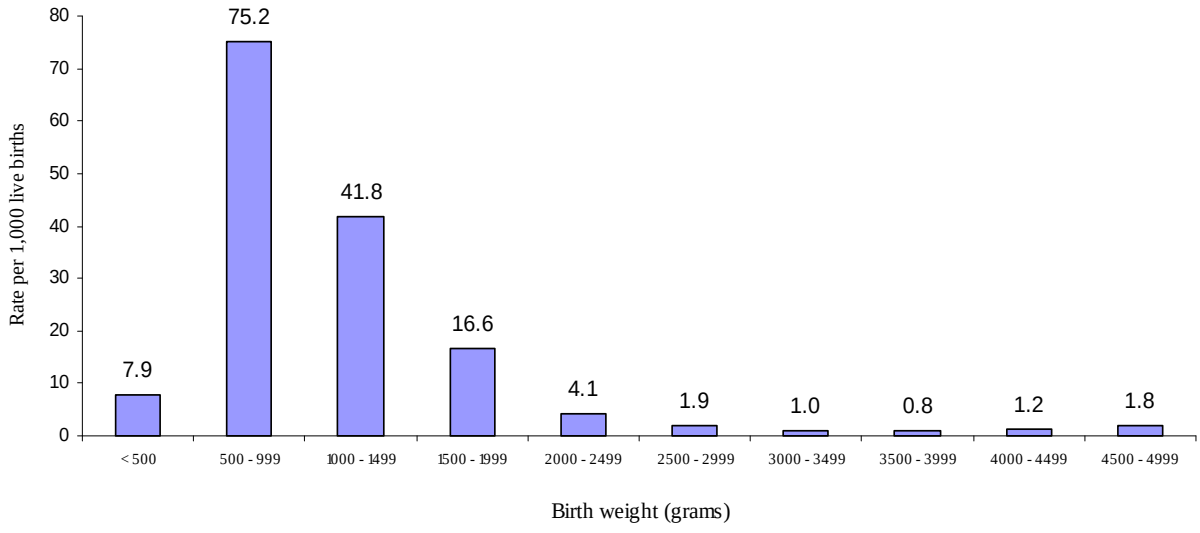
Cerebral palsy by birth weight 1993-2002

Birth weight range (grams)	1993-1997	1998	1999	2000	2001	2002	1993-2002		1993-2002
	No.	No.	No.	No.	No.	No	No.	(%)	Rate[#]
< 500	-	-	-	1	-	-	1	(0.3)	7.9
500 - 999	37	11	3	4	3	-	58	(15.3)	75.2
1,000 – 1,499	28	6	7	5	2	1	49	(13.0)	41.8
1,500 – 1,999	18	7	6	6	2	1	40	(10.6)	16.6
2,000 – 2,499	16	4	3	3	2	3	31	(8.2)	4.1
2,500 – 2,999	33	6	5	5	5	1	55	(14.6)	1.9
3,000 – 3,499	43	6	3	9	6	1	68	(18.0)	1.0
3,500 – 3,999	28	2	3	6	3	5	47	(12.4)	0.8
4,000 – 4,499	12	2	1	1	2	5	23	(6.1)	1.2
4,500 – 4,999	4	-	-	-	1	1	6	(1.6)	1.8
Total	**219**	**44**	**31**	**40**	**26**	**18**	**378**	**(100)**	**2.0**

[#] Rate per 1,000 live births

Figure 4

Rate of cerebral palsy by birth weight 1993-2002



Level of motor function

Tables 7-11 and Figures 5-6 present additional data collected at the 5 year assessment. As only 273 (72%) of notified cases between 1993-2002 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 – 2002. The majority of children had less restricted motor function Levels I and II i.e. walking without restriction (50.9%) and walking without assistive devices (16.8%) respectively, while 31.2% 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

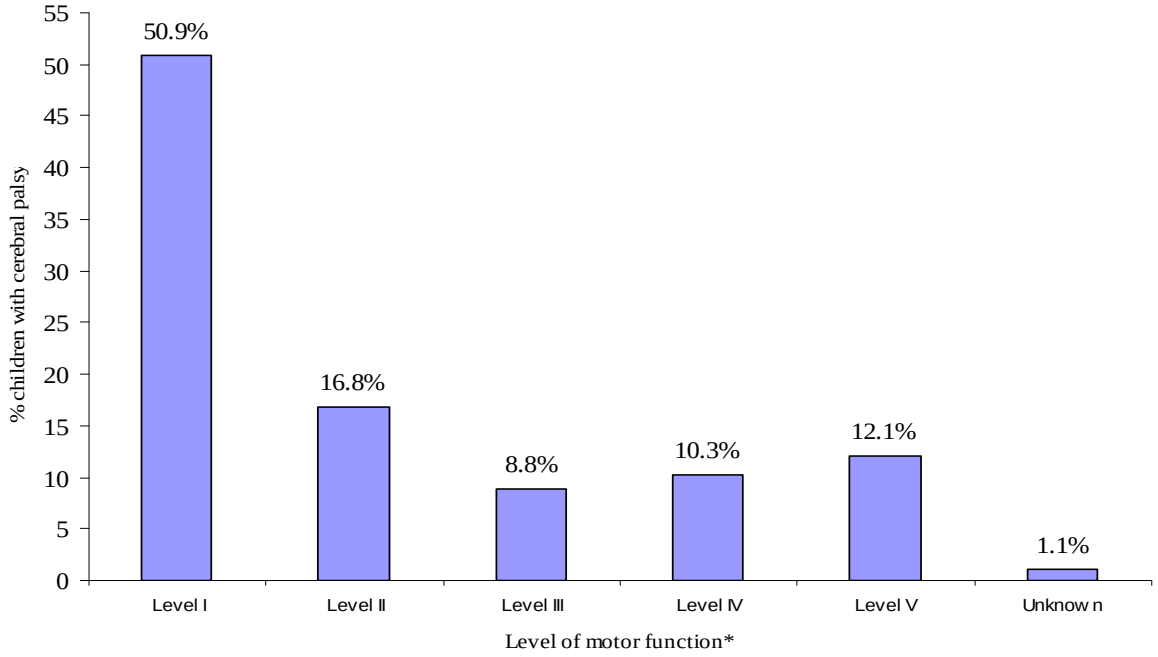
Level of motor function 1993-2002

Level of function*	1993-1997	1998	1999	2000	2001	2002	1993-2002	
	No.	No.	No.	No.	No.	No.	No.	(%)
Level I	83	14	12	18	7	5	139	(50.9)
Level II	38	4	2	1	1	-	46	(16.8)
Level III	15	6	1	1	1	-	24	(8.8)
Level IV	17	1	3	3	2	2	28	(10.3)
Level V	21	7	1	-	3	1	33	(12.1)
Unknown	1	1	-	1	-	-	3	(1.1)
Total	**175**	**33**	**19**	**24**	**14**	**8**	**273**	**(100)**

* Definition of motor function appears in Appendix 1.

Figure 5

Level of motor function 1993-2002



* 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 – 2002. They show that 47.3% of children with cerebral palsy had average or greater intellectual abilities (i.e. an intelligent quotient score of ≥90), 15.4% of children had low average (80-89 I.Q.), 14.7% had mild intellectual disability, and 16.5% had moderate to profound intellectual disability.

Table 8

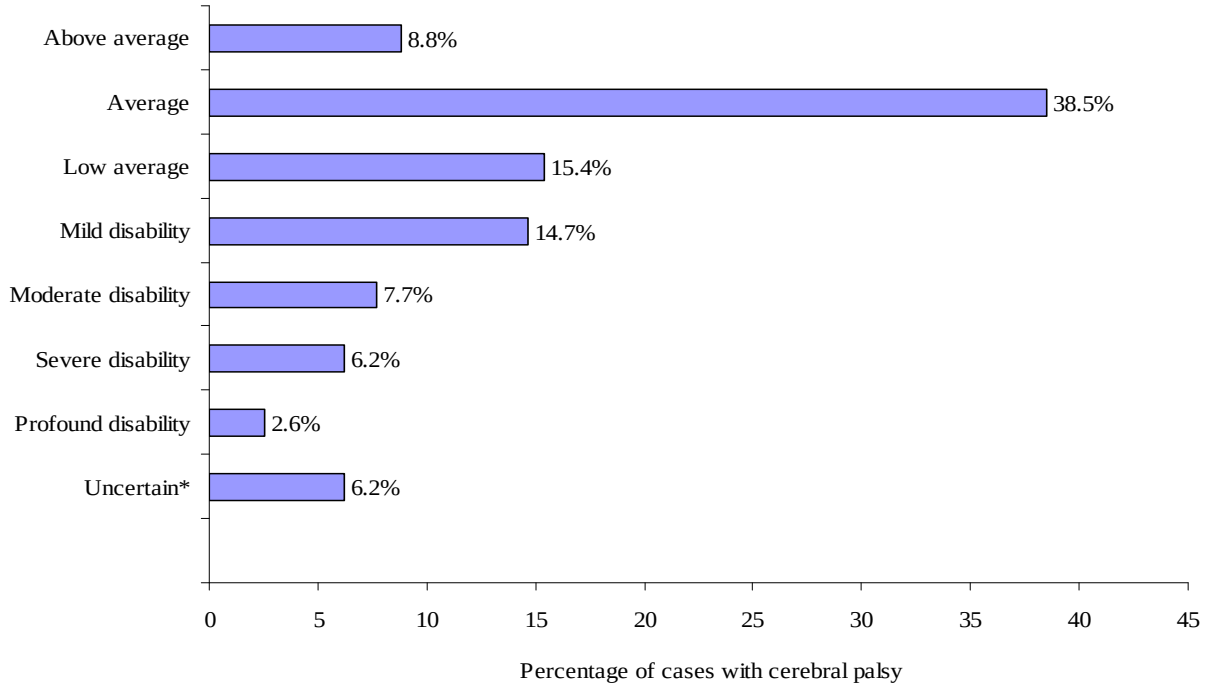
Intellectual ability 1993-2002

Intellectual ability #	1993-1997	1998	1999	2000	2001	2002	1993-2002	
	No.	No.	No.	No.	No.	No.	No.	(%)
Above average	9	6	2	4	1	2	24	(8.8)
Average	67	10	9	12	6	1	105	(38.5)
Low average	30	5	2	2	1	2	42	(15.4)
Mild disability	31	5	1	2	-	1	40	(14.7)
Moderate disability	18	2	-	-	1	-	21	(7.7)
Severe disability	12	1	1	1	2	-	17	(6.2)
Profound disability	2	1	2	-	1	1	7	(2.6)
Uncertain*	6	3	2	3	2	1	17	(6.2)
Total	**175**	**33**	**19**	**24**	**14**	**8**	**273**	**(100)**

#Various scales, appropriate to the child's age and physical abilities, were used to assess intellectual ability.
*Not possible to determine intellectual ability.

Figure 6

Intellectual ability # 1993-2002



#Various scales, appropriate to the child's age and physical abilities, were used to assess intellectual ability.
*Not possible to determine intellectual ability.

Co-morbidities

The frequency of visual problems in children with cerebral palsy born 1993 – 2002 is shown in Table 9. 52% of children had normal vision and 38.5% had impaired vision. In 7% 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

Visual problems 1993-2002

Visual problems*	**1993-1997**	**1998**	**1999**	**2000**	**2001**	**2002**	**1993-2002**	
	No.	**No.**	**No.**	**No.**	**No.**	**No.**	**No.**	**(%)**
Normal	98	11	4	17	8	4	142	(52.0)
Impaired	61	17	12	6	5	4	105	(38.5)
Uncertain	12	4	1	1	1	-	19	(7.0)
Unknown	4	1	2	-	-	-	7	(2.6)
Total	**175**	**33**	**19**	**24**	**14**	**8**	**273**	**(100)**

* 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 – 2002 is shown in Table 10. 83.2% of children had normal hearing and 12.8% of cases had impaired hearing. In 1.8% of cases the level of hearing was uncertain and in 2.2% of cases it was unknown. Impaired hearing includes; sensorineural and/or conductive hearing loss determined by audiology.

Table 10

Hearing problems 1993-2002

Hearing problems*	**1993-1997**	**1998**	**1999**	**2000**	**2001**	**2002**	**1993-2002**	
	No.	**No.**	**No.**	**No.**	**No.**	**No.**	**No.**	**(%)**
Normal	142	29	17	21	12	6	227	(83.2)
Impaired	25	3	2	1	2	2	35	(12.8)
Uncertain	5	-	-	-	-	-	5	(1.8)
Unknown	3	1	-	2	-	-	6	(2.2)
Total	**175**	**33**	**19**	**24**	**14**	**8**	**273**	**(100)**

*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 disablility (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.	(%)
Diplegia	105	11	(10.5)	35	(33.3)	15	(14.3)	26	(24.8)
Right hemiplegia	51	9	(17.6)	17	(33.3)	14	(27.5)	9	(17.6)
Left hemiplegia	47	6	(12.8)	13	(27.7)	14	(29.8)	13	(27.7)
Quadriplegia	40	6	(15.0)	28	(70.0)	25	(62.5)	25	(62.5)
Triplegia	13	2	(15.4)	4	(30.8)	3	(23.1)	4	(30.8)
Ataxia	8	1	(12.5)	5	(62.5)	2	(25.0)	5	(62.5)
Dyskinetic athetoid	6	-	-	2	(33.3)	1	(16.7)	2	(33.3)
Dyskinetic dystonic	2	-	-	1	(50.0)	1	(50.0)	1	(50.0)
Monoplegia	1	-	-	-	-	-	-	-	-
Total (% of total)#	**273**	**35**	**(12.8)**	**105**	**(38.5)**	**75**	**(27.5)**	**85**	**(31.1)**

* Known to have mild to profound intellectual disability

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

Presentations / Conferences / Publications

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 amd 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, 18th-20th 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).

Presentations / Conferences / Publications

Conferences attended by register staff

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

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

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

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

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Annual Reports

1999 - 2007 Annual Reports of the South Australian Cerebral Palsy Register.

Appendix 1

GROSS MOTOR FUNCTION CLASSIFICATION SYSTEM IN CEREBRAL PALSY [6]

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

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)[3].

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 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.

The South Australian Cerebral Palsy Register was established in 1997 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 Public Health Research Unit and is funded by Children, Youth and Women's Health Service, with support from Novita Children's Services, It is a collaboration between the Register, the Paediatric Rehabilitation Service (Children Youth and Women's Health Service) and Novita Children's Services.

The Register contributes 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?

At around five years of age your child will receive a free, comprehensive medical assessment by a paediatric rehabilitation specialist. This assessment will take approximately 45 minutes. 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 Dr Ray Russo, Dr Andrew Tidemann, Dr Deirdre White, Dr James Rice and Dr Phil Egan. 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 them will use it. For example, the Register provides anonymous information about South Australian children with cerebral palsy to the Australian Cerebral Palsy Register for research. *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 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. 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 sign and return the Consent Form in the prepaid envelope provided, (*if you decide not to participate then please let the Register Officer know this by return mail so they 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, and will take approximately 45 minutes. (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 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. 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.
Fax (08) 8161 6088 or E-mail cywhs.cpregister@cywhs.sa.gov.au

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