2005 Annual Report

of

The South Australian Cerebral Palsy Register

(part of The South Australian Birth Defects Register)

Children born 1993 to 2000 with cerebral palsy notified to the Register by 31st December 2005

August 2006

The South Australian Cerebral Palsy Register

Location

Children, Youth and Women's Health Service
Women's and Children's Hospital Campus
Level 8 Rieger Building
72 King William Road
North Adelaide SA 5006
Telephone: (08) 8161 7242
Fax: (08) 8161 6088
Email: cywhs.cpregister@cywhs.sa.gov.au
www.wch.sa.gov.au/services/az/divisions/labs/geneticmed/cerebral_palsy.html

Management Committee

Prof Eric Haan	Clinical Geneticist. Head, SA Clinical Genetics Service
Dr Annabelle Chan	Public Health Physician
Dr Peter Flett	Paediatric Rehabilitation Specialist
Dr Deirdre White	Developmental Paediatrician
Ms Terry Lyons	Acting Director, Client Programs, Novita Children's Service
Ms Phillipa van Essen	Manager, SA Birth Defects Register (on leave 2006)
Ms Heather Scott	Acting Manager, SA Birth Defects Register (2006)
Ms Kylie Tungaraza	Register Officer, Cerebral Palsy Register (until August 2005)
Ms Ann-Maree Davies	Register Officer, Cerebral Palsy Register (2006)

Steering Committee

Women's and Children's Hospital

Dr Peter Flett	Paediatric Rehabilitation Specialist (until July 2005)
Dr Ray Russo	Paediatric Rehabilitation Specialist (since July 2005)

Neonatal Follow-Up Program: Women's and Children's Hospital

A/Prof Ross Haslam	Neonatal Paediatrician

Neonatal Follow-up Program: Flinders Medical Centre

A/Prof Peter Marshall	Neonatal Paediatrician

South Australian Birth Defects Register (SABDR)

Prof Eric Haan	Clinical Geneticist

Collaborating Organisations

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

Funding

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

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

The South Australian Cerebral Palsy Register fulfils a critical role for children with cerebral palsy and their families. This is not only to assist research activities and planning services, but also to assist in our understanding of this complex condition to help establish a better future for affected children.

Many years ago when I began working in Paediatric Rehabilitation after completing my Paediatric training, I was amazed at how little we could offer children with cerebral palsy from a management perspective other than for surgical intervention. Medical technologies were limited to the physical modalities and some oral medications. While these modalities are still critically important, we have recently experienced an explosion in other technologies that can assist children and their families in dealing with the problems associated with cerebral palsy. Many of these technologies are very specific to certain subgroups of children with cerebral palsy, and an accurate assessment of the numbers of children within a community assists greatly in developing these technologies at a local level.

As an example, let us consider the emerging technologies in relation to spasticity management. This is a condition in children with cerebral palsy where tone (or resistance to passive limb movement) is high. This significantly impacts on functional activities, making even simple tasks more difficult to complete. Treating this condition is very important in allowing children to undertake functional activities and participate in their day-to-day lives. As these technologies emerge and are shown scientifically to benefit children with cerebral palsy, there is a need to know how many children could potentially be assisted. Botulinum toxin therapy (a medication injected directly into muscle to reduce tone) has been one recent advance and the South Australian Cerebral Palsy Register data has been used to assist in planning services as the needs for this technology for South Australia can be quantified. *The cerebral palsy register has also assisted in the recruitment of children with a specific form of cerebral palsy for one major intervention research study assessing the use of this medication in the upper limb to enhance functional outcome and participation of the child in daily activities.*

There are other associated difficulties for children with cerebral palsy in relation to complex medical problems, schooling, socialisation, and participation in everyday life. Unfortunately how they impact on an affected child's life is poorly understood, and further research is required in these areas. Many of these difficulties, however, are accurately documented through the register because all children are examined by a rehabilitation specialist at five years of age, and further information about functioning and specific medical complications are recorded. This is a very unique and important feature of the register as the diagnosis can be confirmed (sometimes at a young age what appears to be cerebral palsy is in fact another condition which may not be corrected in the register unless there is a follow-up assessment). This improves the accuracy of the data, as well as provides a comprehensive description of the condition for that particular child. This feature significantly enhances our understanding of the problems experienced by the children and their families.

I have felt that our understanding of cerebral palsy has been greatly enhanced by the activities of the register, and fully support their critical role in assisting children with cerebral palsy realise a better future. I would like to congratulate the management committee for their excellent work in this much-needed area.

Dr Ray Russo, Acting Director of Paediatric Rehabilitation.
Child and Adolescent Development & Rehabilitation,
Women's and Children's Hospital (CYWHS)

Management Committee South Australian Cerebral Palsy Register

Front Row: Ms Heather Scott, Dr Annabelle Chan, Dr Deirdre White,

Back Row: Dr Peter Flett, Ms Kylie Tungaraza, Prof Eric Haan,

Absent: Terry Lyons, Phillipa van Essen, Ann-Maree Davies.

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 18,911 live births per year (1993-2000).

This report presents information for children with cerebral palsy born in the years 1993-2000.

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 spastic quadriplegia, spastic triplegia, spastic diplegia, spastic hemiplegia, monoplegia, ataxia and dyskinesia.

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

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 1993-2000, 330 children with cerebral palsy were ascertained. At 31st December 2005, 67% 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 1993-2000 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 1993–2000 the minimum rate of cerebral palsy was 1.47 per 1,000 live births, and the maximum rate of cerebral palsy was 2.18 per 1,000 live births.

Paediatric rehabilitation specialists notified 44% of cases, Novita Children's Services 27%, the South Australian Birth Defects Register 21%, other specialists 3%, and other sources 4%.

Hemiplegia (34%) and diplegia (33%) were the most common forms of cerebral palsy, followed by quadriplegia (21%), triplegia (4%) and ataxia (3%). Dyskinetic athetoid (2%), monoplegia and dyskinetic dystonic (<1%) were less common forms of the disorder. In 3% of cases, the type of cerebral palsy was unknown.

47.6% of affected children were born at term (≥37 weeks), 52.4% were born prematurely, and none had an unknown gestation.

The association between the risk of cerebral palsy and prematurity is exemplified by a prevalence of 76.8 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).

50.3% of affected children had a birth weight ≥2,500 grams, 18.5% weighed 1,500-2,499 grams, 14.2% weighed 1,000-1,499 grams, and 17% weighed <1,000 grams.

The prevalence of cerebral palsy was 90 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.

66% of affected children had relatively mild cerebral palsy (Levels I and II) while 33% had more severely affected gross motor function (Levels III–V) and 1% of cases had an unknown level of motor function.

34% of children with cerebral palsy born between 1993 and 2000 had impaired intellectual ability, 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 Department of Child and Adolescent Development, Neurology and Rehabilitation of the Women's and Children's Hospital.

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 Phil Egan and Dr Kathy Lee.

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

Acknowledgments

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

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

Special thanks are due to:

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

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 (Badawi et al, 1999) [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 1993-2000. 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 several perinatal factors which are associated, both individually and in combination, with an increased risk of cerebral palsy. These include:

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

Recent research using blood specimens from babies obtained soon after birth, has demonstrated an association between evidence of exposure to infection before birth, markers of prenatal inflammation and certain inherited susceptibilities to thrombosis, and the subsequent development of cerebral palsy. (Gibson et al, 2005, Nelson et al, 1998) [2, 4].

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

Administration

The Register is based at the Women's and Children's Hospital, and is located administratively within the South Australian Clinical Genetics Service. Its location enables it to draw on the experience and expertise of the Department of Child and Adolescent Development, Neurology and Rehabilitation of the Women's and Children's Hospital. The Register's Management Committee is 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 Women's and Children's Hospital, 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 Women's and Children's Hospital.

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

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

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

Data Storage

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

Confidentiality

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

Inclusion and Exclusion Criteria

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

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

Register activities 2005

During 2005, Register staff have:

- Continued to refine the data set, database and systems for analysis and interpretation of data
- Continued to participate in the South Australian Cerebral Palsy Research Group, which is investigating whether variations in genes for clotting factors and perinatal infection are associated with cerebral palsy. This has been a highly productive collaboration, with six articles published in the international peer-reviewed literature in 2005-06.
- Received general queries about setting up a cerebral palsy register from representatives in other Australian States and Territories, and requests for information on consent forms, information pamphlets and legislation.
- Received requests for information from the community and tertiary students who required statistics on the prevalence of cerebral palsy; types of cerebral palsy and associated disabilities in South Australia.
- Received requests for general information about cerebral palsy for Cerebral Palsy Week from the Department of Disabilities Family and Community.
- Continued to collaborate with staff from the Department of Child and Adolescent Development, Neurology and Rehabilitation of the Women's and Children's Hospital as well as staff from the Repatriation General Hospital on a project investigating whether Botox injections can improve upper limb function in children with hemiplegic cerebral palsy.
- Attended the meeting of the Australian Cerebral Palsy Register's (ACPR) State and Territory representatives on Monday 16 and Tuesday 17 May 2005 in Perth to discuss national classification issues and finalise the minimum data set.
- Attended the meeting of the ACPR State and Territory representatives on Saturday 11 March 2006 to discuss the ACPR website, funding issues and the uploading of test data to the ACPR.
- We would like to say thank you to Kylie Tungaraza who left in 2005, for her contribution to the Register and welcome Ann-Maree Davies as the new Register Officer.

Prevalence of cerebral palsy 1993 - 2000

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 - 2000

Group	1993	1994	1995	1996	1997	1998	1999	2000	1993-00	
	No.	No.	No.	No.	No	No	No	No.	No.	(%)
Assessment completed at 5 years	31	32	43	21	41	29	14	11	222	(67.3)
Awaiting assessment	-	-	3	2	2	4	6	13	30	(9.1)
Consents not completed	3	1	1	-	2	3	6	12	28	(8.5)
Medical reports only	2	5	7	5	10	6	4	1	40	(12.1)
Deceased prior to 5 years[#]	1	4	-	1	-	3	-	1	10	(3.0)
Total[*]	**37**	**42**	**54**	**29**	**55**	**45**	**30**	**38**	**330**	**(100)**

[#] Two families had moved interstate.

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

Three hundred and thirty children, born in South Australia (SA) in 1993 – 2000, had been notified to the Register by 31st December 2005. Over this same period, the Register also received 37 notifications of cases born outside SA. A comprehensive clinical assessment at the age of five years has been completed for 222 (67%) of the 330 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 – 2000 (Table 2). The minimum rate represents confirmed cases and the maximum reflects total ascertained cases.

Table 2

Cerebral palsy ascertainment and prevalence 1993-2000

Year of birth	Live births	Ascertained cases	Confirmed cases*		Rate / 1,000[#] min	/ max
1993	19,846	37	31	(84%)	1.56	1.86
1994	19,673	42	32	(76%)	1.63	2.13
1995	19,472	54	43	(80%)	2.21	2.77
1996	18,979	29	21	(72%)	1.11	1.53
1997	18,535	55	41	(75%)	2.21	2.97
1998	18,613	45	29	(64%)	1.56	2.42
1999	18,404	30	14	(47%)	0.76	1.63
2000	17,765	38	11	(29%)	0.62	2.14
1993-2000	**151,287**	**330**	**222**	**(67%)**	**1.47**	**2.18**

*Have completed comprehensive clinical assessment at 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 2000 are shown in Table 3. Over this period, 92% of the notifications came from three main sources, Rehabilitation Specialists, Novita Children's Services and the South Australian Birth Defects Register.

Table 3

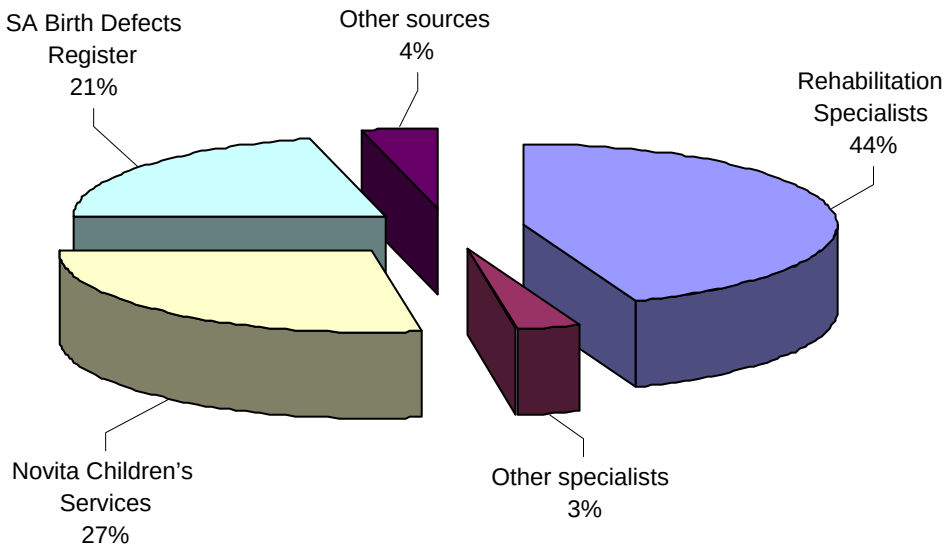
Notifiers to the Register 1993-2000

Notifier*	1993	1994	1995	1996	1997	1998	1999	2000	1993-2000	
	No.	No.	No.	No.	No.	No.	No.	No.	No.	(%)
Rehabilitation specialists	12	5	17	15	31	26	12	26	144	(43.6)
Other specialists	2	-	-	2	4	-	2	1	11	(3.3)
Novita Children's Services	14	33	26	9	2	5	-	-	89	(27.0)
SA Birth Defects Register	5	2	7	3	17	13	12	10	69	(20.9)
Other sources	4	2	4	-	1	1	-	1	13	(3.9)
Unknown	-	-	-	-	-	-	4	-	4	(1.2)
Total	**37**	**42**	**54**	**29**	**55**	**45**	**30**	**38**	**330**	**(100)**

*The Register encourages multiple notifications.

Figure 1

Notifiers to the Register 1993-2000



Type of cerebral palsy

The different types of cerebral palsy for children born in SA between 1993 and 2000 are shown in Table 4. The most common forms of cerebral palsy were hemiplegia, diplegia and quadriplegia accounting for 88% of all cases.

Table 4

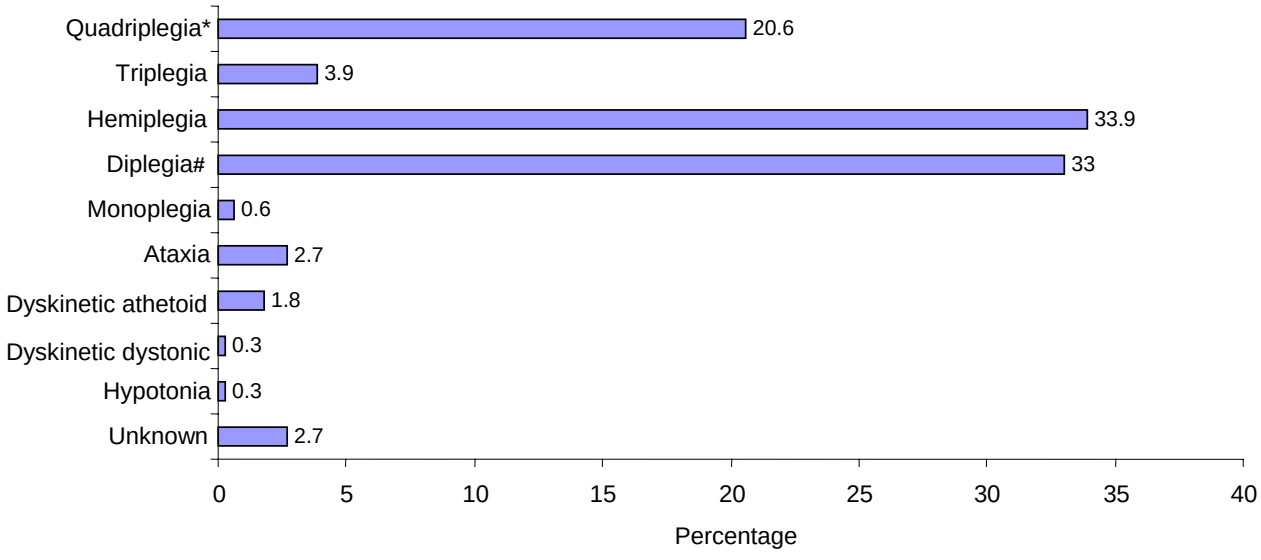
Type of cerebral palsy 1993-2000

Type of cerebral palsy	1993 No.	1994 No.	1995 No.	1996 No.	1997 No.	1998 No.	1999 No.	2000 No.	1993-2000 No.	1993-2000 (%)
Quadriplegia*	7	9	12	3	9	11	9	8	68	(20.6)
Triplegia	1	2	3	4	3	-	-	-	13	(3.9)
Hemiplegia	11	15	18	9	20	12	11	16	112	(33.9)
Diplegia#	16	15	15	11	17	15	8	12	109	(33.0)
Monoplegia	-	-	-	-	-	2	-	-	2	(0.6)
Ataxia	1	-	1	-	1	4	1	1	9	(2.7)
Dyskinetic athetoid	1	-	3	1	1	-	-	-	6	(1.8)
Dyskinetic dystonic	-	-	-	-	1	-	-	-	1	(0.3)
Hypotonia	-	-	1	-	-	-	-	-	1	(0.3)
Unknown	-	1	1	1	3	1	1	1	9	(2.7)
Total	**37**	**42**	**54**	**29**	**55**	**45**	**30**	**38**	**330**	**(100)**

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

Figure 2

Type of cerebral palsy 1993-2000



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

Gestational age at birth

The gestational ages at birth for cases of cerebral palsy born in SA between 1993 and 2000 are shown in Table 5. There were 48% of cases born at term (≥ 37 weeks).

The rate of cerebral palsy by gestational age at birth 1993-2000 is also demonstrated in Table 5 and Figure 3 illustrates the association between cerebral palsy and prematurity (<37 weeks), especially gestations ≤31 weeks.

Table 5

Cerebral palsy by gestational age at birth 1993-2000

Gestation* Weeks	1993	1994	1995	1996	1997	1998	1999	2000	1993-2000		1993 – 2000
	No.	No.	No.	No.	No.	No.	No.	No.	No.	(%)	Rate[#]
23^ - 27	2	6	6	8	12	14	3	3	54	(16.4)	76.8
28 - 31	9	7	14	3	5	7	8	9	62	(18.8)	51.2
32 - 36	6	8	9	3	9	8	6	8	57	(17.3)	6.2
37 - 41	20	21	24	14	29	16	13	18	155	(47.0)	1.1
42+	-	-	1	1	-	-	-	-	2	(0.6)	0.9
Total	37	42	54	29	55	45	**30**	**38**	**330**	**(100)**	**2.18**

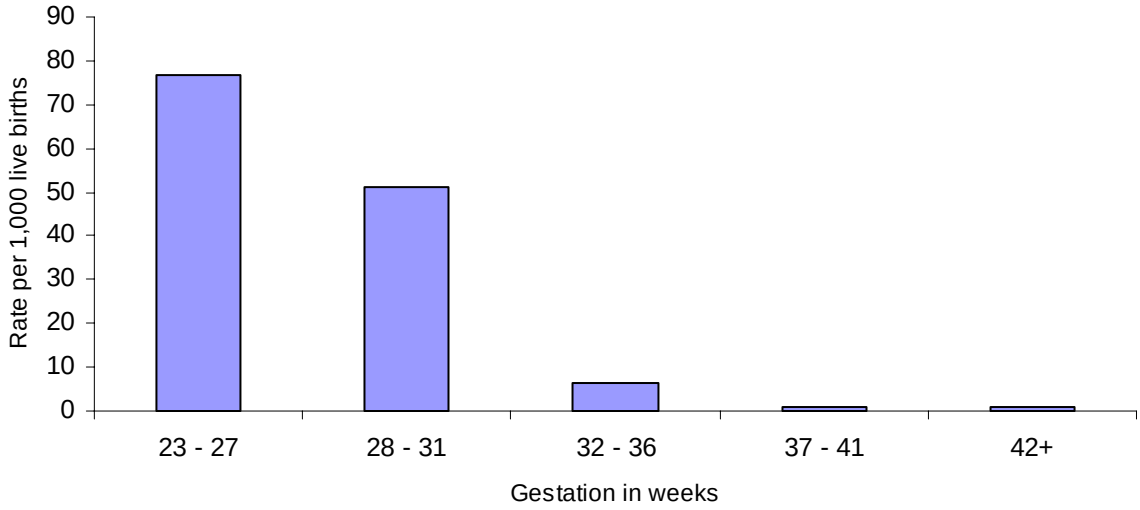
*Gestation at birth (best clinical estimate) in weeks

^ There were no cases below 23 weeks

Rate per 1,000 live births

Figure 3

Cerebral palsy by gestational age at birth 1993-2000



Birth weight

Weight ranges at birth from 1993-2000 are shown in Table 6 and Figure 4.

The rates of cerebral palsy per 1,000 live births, by birth weight, are provided in Table 6 and Figure 4 for the period 1993-2000. They demonstrate a strong relationship between cerebral palsy and low birth weight. As birth weight increases, the rate of cerebral palsy decreases, from 90.0 per 1,000 live births at 500 – 999 g to 0.8 per 1,000 livebirths at 3,500 – 3,999g. The rate increases again for the higher birth weight group, 1.7 per 1,000 live births for birth weights 4,500 – 4,999g.

Table 6

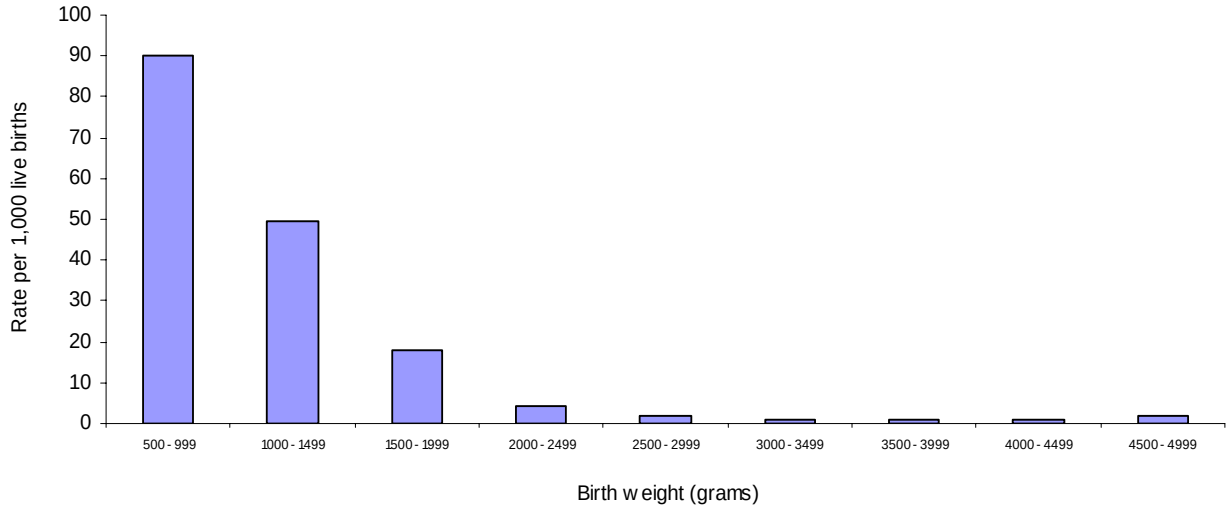
Cerebral palsy by birth weight 1993-2000

Birth weight range (grams)	1993	1994	1995	1996	1997	1998	1999	2000	1993-2000		1993-2000
	No.	No.	No.	No.	No.	No.	No.	No.	No.	(%)	Rate[#]
500 - 999	8	4	11	4	11	11	2	5	56	(17.0)	90.0
1,000 – 1,499	4	8	5	4	7	7	7	5	47	(14.2)	49.5
1,500 – 1,999	3	5	7	2	0	6	6	6	35	(10.6)	17.7
2,000 – 2,499	3	2	3	3	5	4	3	3	26	(7.9)	4.3
2,500 – 2,999	4	5	7	9	8	6	5	5	49	(14.8)	2.1
3,000 – 3,499	7	8	10	4	13	6	4	7	59	(17.9)	1.1
3,500 – 3,999	6	7	6	3	5	3	2	6	38	(11.5)	0.8
4,000 – 4,499	1	2	3	-	6	2	1	1	16	(4.8)	1.1
4,500 – 4,999	1	1	2	-	-	-	-	-	4	(1.2)	1.7
Total	**37**	**42**	**54**	**29**	**55**	**45**	**30**	**38**	**330**	**(100)**	**2.18**

[#] Rate per 1,000 live births

Figure 4

Rate of cerebral palsy by birth weight 1993-2000



Level of motor function

Tables 7-11 and Figures 5-6 present additional data collected at the 5 year assessment. As only 222 (67%) of notified cases between 1993-2000 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 – 2000. The majority of children had less restricted motor function Levels I and II i.e. walking without restriction (48%) and walking without assistive devices (18.5%) respectively, while 32% 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

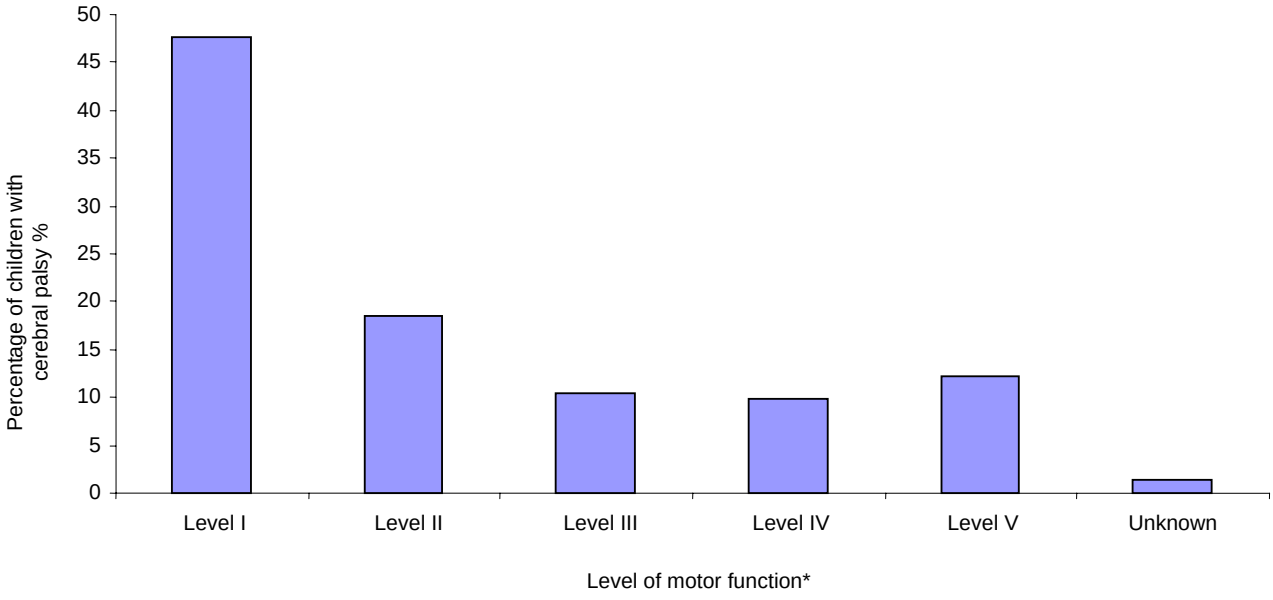
Level of motor function 1993-2000

Level of function*	1993	1994	1995	1996	1997	1998	1999	2000	1993-2000	
	No.	No.	No.	No.	No.	No.	No.	No.	No.	(%)
Level I	9	15	23	11	20	12	9	7	106	(47.7)
Level II	9	9	3	4	11	3	2	-	41	(18.5)
Level III	2	5	4	3	1	6	1	1	23	(10.4)
Level IV	5	1	4	2	5	1	2	2	22	(9.9)
Level V	6	2	9	1	3	6	-	-	27	(12.2)
Unknown	-	-	-	-	1	1	-	1	3	(1.4)
Total	**31**	**32**	**43**	**21**	**41**	**29**	**14**	**11**	**222**	**(100)**

* Definition of motor function appears in Appendix 1.

Figure 5

Level of motor function 1993-2000



* 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 – 2000. They show that 44.1% of children with cerebral palsy had average or greater intellectual abilities (i.e. an intelligent quotient score of ≥90), 15.3% of children had low average (80-89 I.Q.), 17.1% had mild intellectual disability, and 17.1% had moderate to profound intellectual disability. 7.2% of children had above average intellectual ability.

Table 8

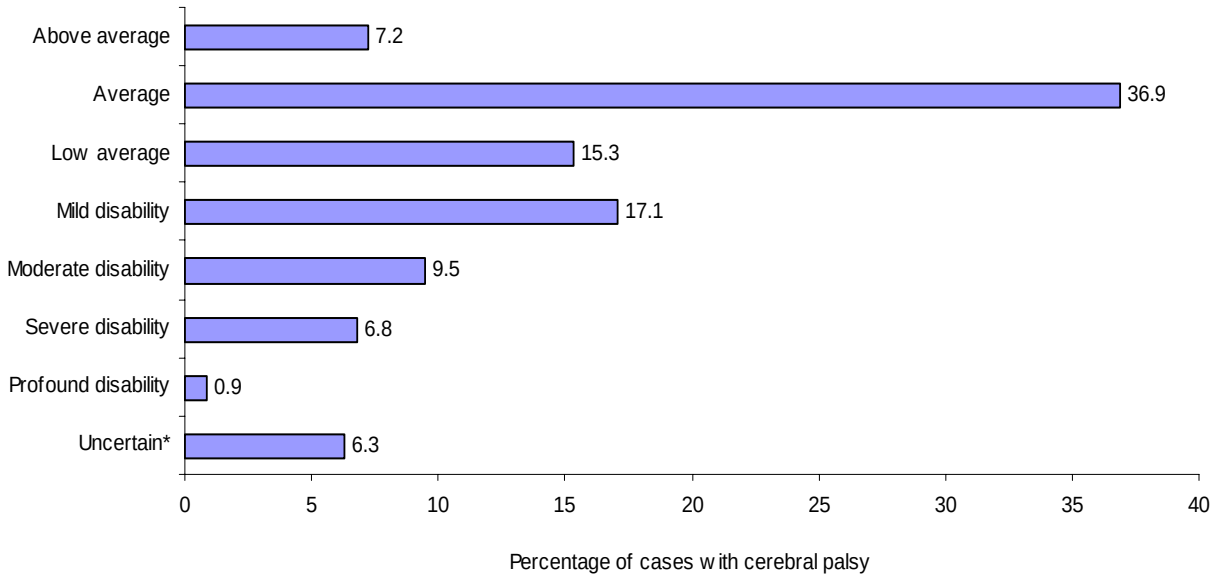
Intellectual ability 1993-2000

Intellectual ability #	1993 No.	1994 No.	1995 No.	1996 No.	1997 No.	1998 No.	1999 No.	2000 No.	1993-2000 No.	1993-2000 (%)
Above average	-	3	2	-	3	4	2	2	16	(7.2)
Average	10	8	13	12	19	10	6	4	82	(36.9)
Low average	5	6	8	5	4	4	2	-	34	(15.3)
Mild disability	3	9	10	2	7	5	1	1	38	(17.1)
Moderate disability	7	3	3	-	6	2	-	-	21	(9.5)
Severe disability	5	2	2	1	2	1	1	1	15	(6.8)
Profound disability	1	1	-	-	-	-	-	-	2	(0.9)
Uncertain*	-	-	5	1	-	3	2	3	14	(6.3)
Total	**31**	**32**	**43**	**21**	**41**	**29**	**14**	**11**	**222**	**(100)**

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

Figure 6

Intellectual ability # 1993-2000



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

Co-morbidities

The frequency of visual problems in children with cerebral palsy born 1993 – 2000 is shown in Table 9. 50% of children had normal vision and 39% had impaired vision. In 8% of cases it was uncertain whether a visual problem was present because of difficulty in assessment eg. due to the level of intellectual disability

Table 9

Visual problems 1993-2000

Visual problems*	**1993**	**1994**	**1995**	**1996**	**1997**	**1998**	**1999**	**2000**	**1993-2000**	
	No.	**No.**	**No.**	**No.**	**No.**	**No.**	**No.**	**No.**	**No.**	**(%)**
Normal	14	14	21	17	27	9	3	6	111	(50.0)
Impaired	13	15	16	4	12	15	8	4	87	(39.2)
Uncertain	4	1	5	-	2	4	1	1	18	(8.1)
Unknown	-	2	1	-	-	1	2	-	6	(2.7)
Total	**31**	**32**	**43**	**21**	**41**	**29**	**14**	**11**	**222**	**(100)**

* Visual problems include; strabismus +/- amblyopia, refractive error, cortical blindness, nystagmus and optic nerve abnormalities.

The frequency of hearing problems in children with cerebral palsy born 1993 – 2000 is shown in Table 10. 82% of children had normal hearing and 13.1% of cases had impaired hearing. In 2.3% of cases the level of hearing was uncertain and in 2.7% of cases it was unknown.

Table 10

Hearing problems 1993-2000

Hearing problems*	**1993**	**1994**	**1995**	**1996**	**1997**	**1998**	**1999**	**2000**	**1993-2000**	
	No.	**No.**	**No.**	**No.**	**No.**	**No.**	**No.**	**No.**	**No.**	**(%)**
Normal	24	24	33	19	34	27	13	8	182	(82.0)
Impaired	6	6	8	2	4	1	1	1	29	(13.1)
Uncertain	1	2	1	-	1	-	-	-	5	(2.3)
Unknown	-	-	1	-	2	1	-	2	6	(2.7)
Total	**31**	**32**	**43**	**21**	**41**	**29**	**14**	**11**	**222**	**(100)**

*Hearing problems include; 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 Quadriplegics, RR=2.22 (1.53, 3.21) p=0.0002, RR=4.02 (2.27, 7.10) p<0.0001 and RR=1.73 (1.25, 2.39) p=0.005 respectively.

Table 11

Type of cerebral palsy and associated disabilities

Type of cerebral palsy	Total in category	Hearing		Vision		Epilepsy		Intellectual disability*	
		No.	(%)	No.	(%)	No.	(%)	No.	(%)
Quadriplegia	35	4	(11)	25	(71)	21	(60)	25	(71)
Triplegia	13	2	(15)	4	(31)	2	(15)	5	(38)
Right hemiplegia	40	7	(18)	12	(30)	10	(25)	18	(45)
Left hemiplegia	31	4	(13)	10	(32)	8	(26)	15	(48)
Diplegia	87	10	(11)	28	(32)	13	(15)	36	(41)
Monoplegia	1	-	-	-	-	-	-	1	(100)
Ataxia	7	1	(14)	4	(57)	2	(29)	4	(57)
Dyskinetic athetoid	6	-	-	2	(33)	1	(17)	4	(67)
Dyskinetic dystonic	1	-	-	-	-	1	(100)	-	-
Hypotonia	1	1	(100)	1	(100)	-	-	1	(100)
Total (% of total)	**222**	**29**	**(13)**	**86**	**(39)**	**58**	**(26)**	**109**	**(49)**

* Known to have intellectual disability of any degree.

Presentations / Conferences / Publications

Presentations

Flett P. Medical Round presentation on “Stroke from a horse, meningitis, and Peliazeus-Merzbacher disease: what do they have in common?” Women’s and Children's Hospital, Adelaide 21st March 2005.

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”, Poster presentation, AusACPDM conference, 18th-20th March 2004.

Flett P. Grand Round lectures on "Botulinum toxin A in cerebral palsy: equalising the race between muscles and bones" to Royal Children's Hospital, Brisbane and to Hervey Bay/Bundaberg Hospitals, Queensland, July/Aug 2002.

Flett P. Invited speaker, 2nd National Symposium on Developmental Paediatrics and Child Neurology, Vellore, South India, October 2002; Four lectures entitled: "Assessment of tone and evaluation of spasticity"; "Cerebral Palsy: overview, management challenges and associated problems"; "Anti-spasticity interventions in cerebral palsy"; "Botulinum toxin A in the management of cerebral palsy".

Flett P. "Beyond the Gait". Workshop convenor and chairperson, Women’s and Children’s Hospital, Adelaide, August 2001.

Boyd R, Noble I, *Flett P*, Corry I, Graham HK. “An economic evaluation of the use of botulinum toxin A, in the conservative management of equinus in children with cerebral palsy”. Presented at the American Academy of Cerebral Palsy and Developmental Medicine (AACPDM) meeting 23rd September 2000, Toronto, Canada.

Conferences

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

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

American Academy of Cerebral palsy and Developmental Medicine meeting, Los Angeles, Sept-Oct 2004. (P. Flett).

Aus ACPDM scientific meeting, Melbourne, March 2004. (P. Flett).

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

Paediatric Epilepsy Workshop, Hyatt Regency Adelaide, 3 May 2003 (P. Flett).

AFRM/RACP annual scientific meeting, Hobart, May 2003 (P. Flett).

Gait Analysis Course, Royal Children’s Hospital, Melbourne, 25-27 June 2003 (P. Flett).

“Has Clinical Gait Analysis Delivered All That it Promised?” Workshop by Prof Kit Vaughan, Adelaide, 24 July 2003 (P. Flett).

State Branch AFRM Scientific Conference, Hahndorf SA, 25-26 October 2003 (P. Flett).

AusACPDM meeting, “Embracing The Evidence”, Sydney, 20th-21st September, 2002 (P. Flett).

2nd National Symposium on Developmental Paediatrics and Child Neurology, Vellore, South India, October 2002 (P. Flett).

Stepping Forward in Cerebral Palsy Management, 14th-15th February 2000, Singapore (P. Flett).

Australian Faculty of Rehabilitation Medicine, 18th-21st August 2000, Melbourne (P. Flett).

American Academy of Cerebral Palsy and Developmental Medicine (AACPDM), September 20th-23rd 2000, Toronto, Canada (P. Flett).

Presentations / Conferences / Publications

Publications utilising data from the Register

Strijbis EMM, Oudman I, van Essen P, MacLennan AH. Cerebral palsy and the application of the international criteria for acute intrapartum hypoxia. Obstet Gynec 2006; 107:1357.

Gibson CS, MacLennan AH, Janssen NG, Kist WJ, Hague WM, Haan EA, Goldwater PN, Priest K, Dekker GA for the South Australian Cerebral Palsy Research Group. Associations between fetal inherited thrombophilia and adverse pregnancy outcomes. Am J Obstet Gynecol 2006; 194, 947.e1–947.e10.

Gibson CS, MacLennan AH, Goldwater PN, Haan EA, Priest K, Dekker GA for the South Australian Cerebral Palsy Research Group. Neurotropic viruses and cerebral palsy: population based case-control study. BMJ 2006; 332(7533):76-80.

Gibson CS, MacLennan AH, Goldwater PN, Haan EA, Priest K, Dekker GA for the South Australian Cerebral Palsy Research Group. The association between inherited cytokine polymorphisms and cerebral palsy. Am J Obstet Gynecol 2006; 194:674 e1-11.

Gibson CS, MacLennan AH, Rudzki Z, Hague WM, Haan EA, Sharpe P, Priest K, Chan A, Dekker GA for the South Australian Cerebral Palsy Research Group. The prevalence of inherited thrombophilias in a Caucasian Australian population. Pathology 2005; 37:160-163.

Gibson CS, MacLennan AH, Hague WM, Haan EA, Priest K, Chan A, Dekker GA for the South Australian Cerebral Palsy Research Group. Associations between inherited thrombophilias, gestational age, and cerebral palsy. Am J Obstet Gynecol 2005; 193:1437.

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

Flett P, An update on the SA cerebral palsy register. Action Packed. Spring 2003.

Gibson CJ, MacLennan AH, Goldwater PN, Dekker GA. Antenatal causes of cerebral palsy: associations between inherited thrombophilias, viral and bacterial infection, and inherited susceptibility to infection. Obstet Gynecol Surv 2003;58:209-20.

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

Gilbert M. What is cerebral palsy? Nexus, November, 2000.

Annual Reports

1999 - 2004 Annual Report of the South Australian Cerebral Palsy Register.

Publications pertaining to cerebral palsy by members of the steering committee

Paper presentation – "Spastic Ankle Equinus Deformity: Management and Functional Outcome in Children with Mitochondrial Encephalomyelopathy" – Baulderstone D, Russo R, Bostock S, Fletcher J. Biennial Australasian Cerebral Palsy & Developmental Medicine (AusCPDM) Conference, Adelaide, Australia. (March 2006)

Poster presentation – "Developmental and Rehabilitation Services for Rural South Australia – A Model for Service Delivery" – Russo R, Cockington RAC. Biennial Australasian Cerebral Palsy & Developmental Medicine (AusCPDM) Conference, Adelaide, Australia. (March 2006)

Poster presentation – "Acquired Brain Injury in Children and Adolescents: Factors That Predict Activity Participation" – Del Fante E, Lane A, Russo R. Biennial Australasian Cerebral Palsy & Developmental Medicine (AusCPDM) Conference, Adelaide, Australia. (March 2006)

Van Zelst BR, Miller MD, Russo R, Murchland S Crotty M. Evidence for activity and participation restriction in children with hemiplegic cerebral palsy: a cross-sectional evaluation using the Assessment of Motor and Process Skills in a familiar home environment. Dev Med & Child Neurol (In press)

Flett P, Russo R. Large heads, hydrocephalus and neural tube defects. In Robinson MJ, Roberton DM, ed. Practical Paediatrics 6th Edition. Churchill Livingstone, Melbourne. (In press)

Book review on Handbook Of Early Childhood Intervention, 2nd edition, edited by JP Shonkoff and SJ Meisels; 2000. New York: Cambridge University Press. pp. xx + 734; includes index. J. Paed. Child Health 2005; 41, 309.

Flett P, Review article, "Rehabilitation of spasticity and related problems in childhood cerebral palsy". J Paed Child Health 2003; 39:6-14

Letters to the Editor, "Indications for Use of Botulinum Toxin in Children with Cerebral Palsy", J. Bone Joint Surg. Am. 2004; 86:1. Graham H.K., Baker R., Boyd R. and Flett P. In response to Scientific Article by Kay RM et al "Botulinum Toxin as an Adjunct to Serial Casting Treatment in Children with Cerebral Palsy" J. Bone Joint Surg. Am. 2004; 86:2377-2384.

"Cerebral Palsy and paediatric neuro-rehabilitation" Flett P.J. and Graham H.K.in Textbook of Neural Repair and Rehabilitation, Vol. 11, pp. 636-656, Cambridge University Press Feb. 2006

Flett P. Book review: "Congenital hemiplegia", Neville B and Goodman R; eds., 2000. J Paed Child Health 2002; 38:324.

Houltram J, Noble I, Boyd RN, Corry I, Flett P, Graham HK. Botulinum toxin type A in the management of equinus in children with cerebral palsy: an evidence-based economic evaluation. Eur J Neurol 2001; 8:S194-202.

Beal SM, Zeitz H, Connell T and Zschorn M. Athetoid quadriplegia and literacy. J Paed Child Health 2000; 36:389-391.

Flett P, Ferris R, McDonnell K, Raymond J, Walters G. Food for thought for people with disabilities and their carers. Ed. Sheedy C.T. Major revised edition. Project funded by Department of Human Services, Health Promotion SA, 1999.

Flett PJ, Stern LM, Waddy H, Connell TM, Seeger JD, Gibson SK. Botulinum toxin A versus fixed cast stretching for dynamic calf tightness in cerebral palsy. J Paed Child Health 1999; 35:71-77.

Appendix 1

GROSS MOTOR FUNCTION CLASSIFICATION SYSTEM IN CEREBRAL PALSY[3]

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.

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

What is the purpose of the Register?

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

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

What benefits are there for my child?

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

What other benefits may come from participating?

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

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

Who are the Register staff we will have contact with?

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

How will information about my child be kept confidential?

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

Are there any risks for my child?

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

Has the Register received approval from an Ethics Committee?

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

How do I give my consent?

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

What happens now?

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

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

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

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

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

References

1. Badawi N, Watson L, Petterson B, Blair E, Slee J, Haan E, Stanley F. What constitutes cerebral palsy? Developmental Medicine & 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. 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 & Child Neurology 1997; 39: 214-223.

4. Gibson CJ, MacLennan AH, Goldwater PN, Dekker GA. Antenatal causes of cerebral palsy: associations between inherited thrombophilias, viral and bacterial infection, and inherited susceptibility to infection. Obstet Gynecol Surv 2003; 58: 209-20