



**W**elcome to the fourth newsletter of the Victorian Cerebral Palsy Register (VCPR). We are extremely grateful to you, the families, for your commitment to the Register, and for your participation in research projects. This newsletter informs you of our progress to date and highlights some of the recent findings that have come from our research.

Sixteen PhD students have used the VCPR for their projects. Sue Reid, the Manager of the VCPR completed her PhD in 2012. Her thesis was titled "Cerebral palsy in Victoria: a population-based study". In May 2013, Elaine Meehan, the research assistant working with the VCPR, has just commenced her PhD studies on access, affordability and quality of health care for children with cerebral palsy.

Every three years, the VCPR provides information (without identifying individuals) to the Australian Cerebral Palsy Register. The second report on cerebral palsy in Australia was released in April 2013. The report can be viewed online at [www.cpregister.com](http://www.cpregister.com).

We would be delighted to hear from you to get your feedback and to answer any of your questions.

**Our contact details:**

**Sue: 9345 4807**

**Elaine: 9345 4808**

**Tess: 9345 4562**

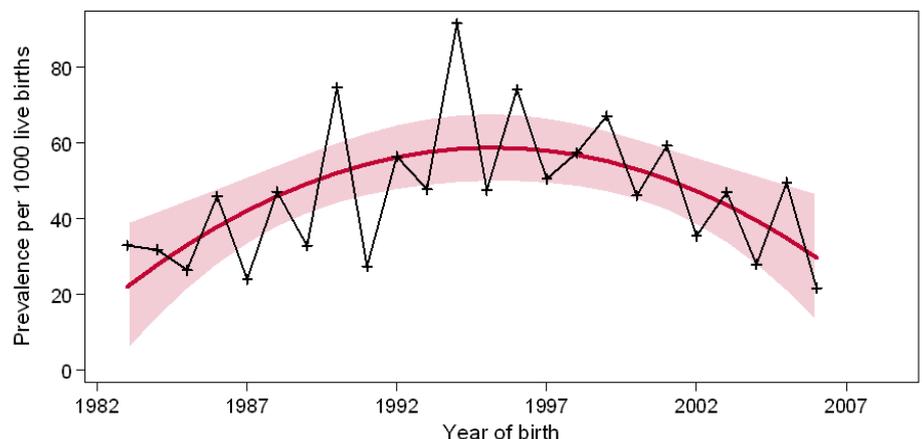
**Email: [vic.cpregister@rch.org.au](mailto:vic.cpregister@rch.org.au)**

## OUR PROGRESS TO DATE

The Victorian Cerebral Palsy Register (VCPR) now holds information on 5039 individuals with cerebral palsy who were born since 1970. Most (91%) were born in Victoria and the rest have moved to Victoria from another state or overseas. It is great that 45% of families of individuals 18 years or younger have consented to be contacted by the VCPR for research studies. To date, 55 separate research projects have used the VCPR in some way, and many of them have required family participation. We really appreciate the fantastic response from families for these projects.

Research arising from the VCPR has been published in medical journals. The current number of publications stands at 60. In October 2012, five papers were presented at the International Cerebral Palsy Conference in Pisa, Italy. These included talks on brain MRI findings in cerebral palsy, changes in the rates of cerebral palsy over time and speech and language problems in young children with cerebral palsy.

For those interested in the bigger picture, information from the VCPR (published in 2011) shows that the rate of cerebral palsy in the most premature infants (those born earlier than 28 weeks gestation) has been decreasing since the late 1990s following a previous increase in rates over the 1980s and early 1990s. In the mid 1990s, around 6% of extremely premature infants were diagnosed with cerebral palsy but the percentage dropped to only about 3% in 2006. The graph below demonstrates this reduction. This good news is likely to reflect improvements in the care of these fragile newborns in the neonatal intensive care unit.



## COMMUNICATION SKILLS IN CHILDREN WITH CEREBRAL PALSY

In 2011, Cristina Mei, together with her PhD supervisors Angela Morgan, Sheena Reilly, Dinah Reddihough and Fiona Menash, began a study looking at the communication skills of children with cerebral palsy aged between 5 and 6 years. Between October 2011 and November 2012, 84 children from the VCPR had a full speech and language assessment.

Initial results from this research show:

- ◆ 76% of children with cerebral palsy communicate verbally, while 24% communicate using non-verbal methods.
- ◆ 60% of children in this study demonstrated language problems (i.e. difficulty in understanding or producing sentences).
- ◆ 60% of children demonstrated speech problems (i.e. difficulty in saying sounds).
- ◆ In total, 80% of the children studied demonstrated some speech and/or language difficulties.

The researchers are currently trying to find out why some children with cerebral palsy demonstrate communication difficulties and how these problems affect children's day-to-day tasks.

We would like to thank all the families who generously participated in this project. Your help has been greatly appreciated.



Victorian Cerebral Palsy Register,  
Murdoch Childrens Research Institute,  
Royal Children's Hospital,  
50 Flemington Road,  
Parkville, VIC 3052

## COGNITIVE OUTCOMES IN CHILDREN WITH CEREBRAL PALSY

Sarah Sherwell looked at the thinking and learning abilities of young children with cerebral palsy as part of her PhD research. Between July 2008 and March 2011, eighty children had an assessment with a neuropsychologist as part of this project.

There were three main findings:

- ◆ We found that it was difficult for many children with cerebral palsy to take part in assessments that psychologists normally use to assess thinking and learning ability. Many children did not have the speech and movement ability to complete tasks and 38% of the children were unable to finish all of the assessment tasks.
- ◆ For the children who did complete the thinking and learning tasks, we found most of them scored within the range expected for their age, but lower than children who do not have cerebral palsy.
- ◆ Twenty-five percent of parents reported their child had some difficulty with emotional and behavioural problems.

These results suggest that children with cerebral palsy may need extra support to help them with their thinking, learning and behaviour. Psychologists must consider a child's movement and speech difficulties when they are assessing thinking and learning abilities so that a child's results are a true indication of their ability.

## CLINICAL FEATURES IN CHILDREN WITH WHITE MATTER INJURY AND CEREBRAL PALSY

The aim of this project was to learn more about the clinical characteristics of children aged 4 to 12 years with cerebral palsy who have white matter changes on their MRI brain scans. We were interested in comparing the clinical characteristics for children who were born at or before 34 weeks gestation with those born after 34 weeks. Between January 2011 and June 2012, 109 children had an assessment with a physiotherapist and occupational therapist.

Our results found:

- ◆ There was no difference in the type of movement problems experienced by children born at or before 34 weeks and those born after 34 weeks.
- ◆ More children born at or before 34 weeks had movement difficulties affecting both sides of their bodies compared with those born after 34 weeks.
- ◆ Children born after 34 weeks were found to have fewer problems with moving their bodies, using their hands and communicating than children born at or before 34 weeks gestation.

These results provide important information about how this group of children communicate, use their hands and move their bodies. These results have been presented at two international conferences and we are now preparing a journal article for publication.