



Welcome to the sixth newsletter of the Victorian Cerebral Palsy Register (VCPR). We have been busy over the past six months and have many events and research projects to update you on.

In this issue, we have included some up-to-date statistics on cerebral palsy (CP) in Victoria in 2014. We also provide an update on some of our current research projects. You may receive invitations to participate in some of these projects over the coming months. A number of student researchers are working with us at the moment and carrying out some exciting research. Their projects are outlined on page 3 of the newsletter.

Many of our researchers attended the recent conference of the Australian Academy of Cerebral Palsy and Developmental Medicine where the findings of a number of research projects that involved the VCPR were presented to other medical professionals and researchers from Australia and overseas. Some of our colleagues are currently planning a number of clinical trials, including a trial of cord blood for treating CP and a trial of medication for the movement disorder dystonia. These trials are still in the planning stages but look out for further information in our future newsletters. The work of the Centre for Research Excellence in CP has also begun. Watch this space!

We are extremely grateful to you, the families, for your commitment to the Register and for your participation in research projects. If you have any questions or would like some more information about any of our projects, please feel free to contact us. Our contact details are provided below.

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Follow-up of children on the VCPR

We are continuing to invite children to attend an assessment with a research physiotherapist or occupational therapist at the Royal Children's Hospital after they turn five, ten or fifteen years of age.

The aim of this research is to collect information on each child's abilities and to monitor changes in their movement problems as they grow older. To date, over 150 children have had one of these assessments. Please look out for your child's invitation to participate in this research project. The assessment can be held on the same day that your child is attending the hospital for another medical appointment and it takes less than thirty minutes.

We are grateful to the Victorian Medical Insurance Agency for continuing to fund this project.

Cerebral palsy in Victoria: an update

- ◆ CP is the most common cause of childhood physical disability worldwide.
- ◆ There are a total of **5,149** individuals registered on the VCPR, born since 1970. The majority of these individuals were born in Victoria, but some have moved here from interstate or overseas.
- ◆ There are currently **2,270** children aged less than 18 years registered on the VCPR.
- ◆ **42%** of children registered on the VCPR were born pre-term (ie before 37 weeks gestation). In the general Australian population, around 8% of babies are born pre-term.
- ◆ **12%** of children registered on the VCPR were from a multiple birth (ie twins or triplets).

We use the **Gross Motor Function Classification System (GMFCS)** to describe the abilities of each individual on the VCPR. The GMFCS is used internationally by doctors, therapists and researchers. We thought you might be interested in knowing a bit more about the GMFCS scale. The descriptions below refer to children's



GMFCS I: Children classified as GMFCS I are minimally impaired. They can move around independently, walk indoors and outdoors, and climb stairs, and be able to run and jump, but their speed, balance and coordination may

36% of children registered on the VCPR are classified as GMFCS I.



GMFCS II: Children classified as GMFCS II can move around independently but may require some assistance for walking longer distances or on uneven surfaces. They have a limited ability to perform skills such as running and jumping.

26% of children registered on the VCPR are classified as GMFCS II.



GMFCS III: Children classified as GMFCS III can walk with a hand-held device on level surfaces but often use a wheelchair for long distances or when outdoors on uneven terrain.

10% of children registered on the VCPR are classified as GMFCS III.



GMFCS IV: Children classified as GMFCS IV may be able to walk short distances at home with the help of a walker. For longer distances, they will use a manual or a powered wheelchair.

13% of children registered on the VCPR are classified as GMFCS IV.



GMFCS V: Children classified as GMFCS V use a wheelchair for all transportation. Some children may be able to get around independently using a powered wheelchair that has been adapted to meet their needs.

15% of children registered on the VCPR are classified as GMFCS V.

Our student researchers

The management of respiratory illness in children with CP

Over the coming winter months, a medical student from Monash University, Dhanu Giritharan, will be talking to parents of children with CP who present with a respiratory problem to the emergency department at the Royal Children's Hospital. Dhanu is doing a research project under three departments at RCH: Developmental Medicine, Emergency, and Respiratory Medicine. His supervisors include Dinah Reddihough and Sue Reid.

As part of the study, Dhanu will be seeking parent's consent to collect information from each child's medical record, including their medical details, the complaint that brought them to emergency, as well as tests performed, drugs prescribed and other treatments performed, either in the emergency department or in the ward (in the event the child was admitted). Dhanu will also collect information on the child's

Parent satisfaction with inpatient care at the Royal Children's Hospital

Maria Ianelli, a medical student from the University of Melbourne is working with her supervisors Dinah Reddihough, Adrienne Harvey and Jenny O' Neill to learn more about the experiences of parents who have children admitted to the Royal Children's Hospital. She is interested in the experiences of parents who have children with CP compared to parents of children without a disability.

Over the coming months, the parents of children with CP admitted to the General Medical (Sugarglider), Adolescent and Rehabilitation (Kelpie) and Orthopaedic (Platypus) wards at the Royal Children's Hospital may be invited to complete a short survey on the child's care while an inpatient and the parent's overall experience of being in the hospital. Maria will also be asking the parents of children without a disability

Access, cost and quality of care for Victorian children with CP

Elaine Meehan, a PhD student at the University of Melbourne, is continuing her research looking at the use of medical services by Victorian children and adolescents with CP. It is hoped that by understanding the patterns of use of different medical services, the delivery of services for children with CP will be improved.

One part of her research involves asking parents to complete a survey about their child's visits to general practitioners (GPs) and paediatricians. She is inviting parents to complete the survey which can be com-

Recent scientific publications from the VCPR

Reid, SM., Dagia, CD., Ditchfield, MR., Carlin, JB. & Reddihough, DS. 2014. Population-based studies of brain imaging patterns in cerebral palsy. *Developmental Medicine and Child Neurology*, 56, 222-232

Reid, SM., Dagia, CD., Ditchfield, MR., Carlin, JB., Meehan, EM. & Reddihough, DS. An Australian population study of factors associated with MRI patterns in cerebral palsy. *Developmental Medicine and Child Neurology*, 56, 178-184

Harvey, A., Randall, M., Reid SM., Lee, K., Imms, C., Rodda, J., Eldridge, B. & Reddihough DS. 2013. Children with cerebral palsy and periventricular white matter injury: does gestational age affect functional outcome? *Research in Developmental Disabilities*, 34, 2500-2506

Reddihough D., Jiang, B., Lanigan, A., Reid, S., Walstab, J. & Davis, E. 2013. Social outcomes of young adults with cerebral palsy. *Journal of Intellectual and Developmental Disability*, 38, 215-22

The Australasian Academy of Cerebral Palsy and Developmental

Many of our researchers attended the 7th Biennial conference of the Australian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM) which was held recently in the Hunter Valley, New South Wales. This year's conference "*Breakthrough to Excellence*" gave clinicians and researchers from Australia and overseas the opportunity to present and discuss the latest research findings and advances in childhood disability research.

VCPR presentations

Sue Reid presented some of the findings of her MRI research, as well as her research on perinatal stroke in children with CP. Dinah Reddihough presented the findings of Cristina Mei's PhD research on activity and participation of children with CP with communication impairment. We also presented a poster outlining the findings of a study carried out last year which involved surveying the parents of many children on the VCPR about the types of therapy their child receives.

Cerebral Palsy Support Network

The Cerebral Palsy Support Network (CPSN) is a not-for-profit organization providing information and support services to people living with CP and their networks. They help empower people to lead more independent lives and provide support in a variety of ways to their families and networks. At the CPSN, the focus is on providing the best possible service for all members.

What services does the CPSN provide?

- ◆ Cerebral Palsy Innovative Choices Program (select your own support worker)
- ◆ Social, health and recreational programs for people with CP
- ◆ Members-only access to website resources and information library
- ◆ Information seminars and workshops
- ◆ Carer support groups
- ◆ Speaker presentations
- ◆ Members Trust Fund
- ◆ Care Centre including phone and face-to-face support, intake and referral services

Membership is free to people with CP and their families!

To join, call the CPSN office during business hours or apply online through the website.

525 High Street, Preston VIC 3072

Email: cpsn@cpsn.org.au

Phone: (03) 9478 1001 or 1300 277 600

Website: www.cpsn.org.au



Developmental Medicine, RCH: parent education and training

Developmental Medicine at the Royal Children's Hospital, is a multidisciplinary team of specialists who promote the highest standards of care for children with developmental disabilities and their families.

Developmental Medicine staff host regular webinars for parents and carers on a range of disability related topics. These webinars are free of charge to parents. You can sign up to their mailing list to be kept in the loop about education and training events. You will get occasional, brief, targeted, relevant information by email. This e-newsletter is suitable for parents/carers, paediatricians, GP's, nurses, health professionals, education professionals and anyone with an interest in education and training related to developmental disability.

How can I find out more?

Visit The Learning Hub, the home of Developmental Medicine's education and training events, to see the full range of upcoming events and to access a growing library of disability focused e-resources. You can also sign up to the Developmental Medicine Mailing list [here](#).

Website: <http://www.learninghub.org.au/course/category.php?id=49&viewtype=course>