

CP Register

Victoria



Victorian Cerebral Palsy Register newsletter

Issue 7, December 2014

Welcome to the seventh newsletter of the Victorian Cerebral Palsy Register (VCPR). It has been a busy year for us. Some members of our team recently attended the annual meeting of the American Academy of Cerebral Palsy and Developmental Medicine in San Diego. They participated in a workshop on cerebral palsy registers, teaching researchers from around the world on the importance of these registers, and how to go about setting up and running one.

We have been involved in recruiting participants for a number of research studies, including a study on upper limb functioning and a study investigating epilepsy in children with cerebral palsy. Elaine Meehan is continuing her PhD research looking at the health service needs of children and adolescents with cerebral palsy, and Sue Reid's project "understanding the causes of cerebral palsy" is currently underway. A trial of cord blood for treating cerebral palsy is still in the planning stages; hopefully we will be able to provide you with more information on this trial in 2015.

As always, we are extremely grateful to you, the families, for your commitment to the VCPR and for your participation in research. If you have any questions, please get in touch.

**Seasons greetings from the VCPR team!
Wishing you and your family all the best
for 2015.**



Follow up of children on the VCPR

This project aims to follow up children with cerebral palsy as they grow. By collecting information on each child's abilities throughout childhood and adolescence, it is hoped that we will gain a greater understanding of how each child changes as they grow.

So far, 165 children have attended an assessment with a physiotherapist and/or occupational therapist. Please look out for your child's invitation to take part around the time of their fifth, tenth or fifteenth birthday.

The assessment can take place on the same day that your child is attending the Royal Children's Hospital for another medical appointment, and it takes around 30 minutes.

We would like to thank the Victorian Medical Insurance Agency for providing financial support for this project.

The Centre for Research Excellence in Cerebral Palsy (CRE-CP)

The CRE-CP is a five year project funded by the National Health and Medical Research Council that aims to improve the health and well-being of people affected by cerebral palsy. It is based in Melbourne, but involves a team of expert cerebral palsy researchers from around Australia and overseas. It has been an exciting few months, with three PhD projects now taking applications, a clinical trial of hip management recruiting participants (CP-HIP), and the launch of a brand new website. The CRE will also focus on supporting the mental health and well-being of carers. We will be working in partnership with parents to develop a solution-based research program.

Researchers will be looking for parents, carers and persons with cerebral palsy to have discussions about two key areas: experiences of hip surveillance, and identifying priorities for mental health. If you would like to be involved in either of these projects please contact the CRE-CP co-ordinator, Tessa Devries, or visit the website (details below). There will be more projects open for involvement throughout the course of the CRE; to be among the first to hear about them please join the CRE-CP online mailing list by visiting the following webpage: <http://eepurl.com/VgLoP>

CRE-CP website: www.cre-cp.org.au

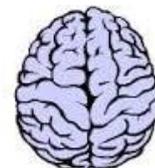
Phone: 9936 6087 **Email:** cre.cp@mcri.edu.au



Current Research

Understanding the causes of cerebral palsy

The first part of this project involves describing the patterns of abnormality on MRI scans of the brain in children with cerebral palsy in more detail and classifying them. We will then examine relationships between MRI findings and clinical outcomes for these children, and identify factors that increase the risk of cerebral palsy in groups based on their brain scan. We are currently inviting families to participate in the study. Children need to be born in Victoria between 1999 and 2008 and have brain scans classified to one of four patterns of abnormality. Natural mothers of children are being invited to consent to the collection of additional data on risk factors from the Victorian Perinatal Data Collection and Birth Defects Register, complete a maternal questionnaire, and collect saliva samples from the child that will be stored for later use.



For more information on this study, please contact:

Angela Guzys: **Tel:** 03 9936 6089 **Email:** angela.guzys@mcri.edu.au

Motor training and hand splinting – helping children reach their goal

Children with cerebral palsy aged 4-15 who have goals related to their hand function and would be able to communicate with a therapist and participate in group therapy are being invited to participate in a new research study. This study aims to use motor training to enable children with cerebral palsy to reach their goals related to using their hands. It involves an assessment, 2 weeks of treatment and a follow-up assessment two months after treatment. Treatment will take place at Monash Children's Hospital from **Monday 12th to Friday 23rd January, 2015**.

For more information on this study, please contact:

Michelle Jackman: **Tel:** 0402 502 111 **Email:** michelle.jackman@hnehealth.nsw.gov.au

Dr Brian Hoare: **Email:** brian.hoare@monashhealth.org

Seizures in children with cerebral palsy and white matter injury

The aim of this project is to learn more about the types of seizures in children with cerebral palsy. This information will help us to understand the different types of epilepsy in children with cerebral palsy and make decisions about treatment. Children with cerebral palsy who have already had an MRI of the brain demonstrating white matter injury are being invited to participate. Parents will be asked a range of questions about their child's cerebral palsy and whether or not they are having seizures. This can be completed over the telephone.

For more information on this study, please contact:

Dr Monica Cooper: **Tel:** 03 9345 5898 **Email:** monica.cooper@rch.org.au

Parent/carer education and training opportunities

The department of Developmental Medicine at the Royal Children's Hospital hosts regular webinars for parents and carers on a range of different disability-focussed topics. To see the range of webinars and other events being held in 2015, and to sign up to the mailing list, please visit the webpage: <http://www.rch.org.au/cdr/>

If you would like to receive future newsletters and other correspondence by email, please send an email with your preferred email address to vic.cpregister@rch.org.au

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Dinah Reddihough honoured with Health Lifetime Achievement Award

In October, Dinah Reddihough was awarded a Health Lifetime Achievement Award at the Victorian Public Healthcare Awards. This award recognises outstanding careers in health, achieved over a lifetime of service in the Victorian health system. It is the highest honour for an individual, in recognition of their dedication, commitment and achievements in health.

Congratulations, Dinah!