

July, 2016

Welcome to the 10th newsletter of the Victorian Cerebral Palsy Register (VCPR)!

We have just returned from the International Conference on Cerebral Palsy and other Childhood-onset Disabilities which was held in Stockholm, Sweden. Researchers and clinicians from our team presented on a range of topics including changes in cerebral palsy (CP) rates in Victoria, dystonic CP, saliva control, as well as brain imaging patterns, bike riding skills, hospital admissions, and epilepsy in children with CP. It was a great opportunity to hear about what is happening internationally in the field of cerebral palsy research, and to share with others what we are doing here in Australia.

Earlier in the year, we presented some of our research at the Australasian Academy of Cerebral Palsy and Developmental Medicine conference which was held in Adelaide. Sue Reid, manager of the VCPR, won a Best Paper prize for her work examining trends on cerebral palsy prevalence and severity in Victoria over the past few decades. Her research has shown that the proportion of children with severe cerebral palsy appears to be dropping which is very good news.

Over the past 6 months or so, we have invited families to take part in a number of research studies, with the study topics including bike riding skills, hip surveillance and parent wellbeing among others. We would like to say a huge thank you to families that took part—your involvement is much appreciated by all of the researchers involved. Over the next 6 months, we will be involved in recruiting participants for studies on various topics including stem cells, respiratory health, bone health, and arm splinting in individuals with CP, and you may receive invitations to take part if we think you or your child would be eligible.

We are trying to reduce our paper use (and postage costs!) so if you would like to receive future newsletters and other correspondence via email, please let us know by sending an email to vic.cpregister@rch.org.au.

As always, if you have any questions, please feel free to contact us by email or telephone on 03 9345 4808 (Elaine) or (03) 9345 4807 (Sue).

Parent education resources

Webinar: How can an Occupational Therapist help you and your child with Autism Spectrum Disorder?

Date: Wednesday 20th July 2016

Time: 1.00pm-2.00pm

Presenter: Ms Charmaine Bernie, Senior Occupational Therapist, Autism Research Team, RCH

Occupational Therapists (OTs) have been working to support children with Autism Spectrum Disorder (ASD) and their families for over 30 years. Whilst there is more known now than ever before about the common occupational difficulties experienced by young people diagnosed with ASD, confusion and variation remains around the scope of practice of OTs working with these children and families.

This webinar will explore the history and current trends in evidence-based practice for occupational therapists who provide ASD-related services. The value that they add to the assessment and goal-setting process will be discussed, along with the latest evidence on interventions carried out by OTs in this field of practice.

Find out more and register here: <http://blogs.rch.org.au/devmed/2016/06/16/live-webinar-for-parents-occupational-therapy-and-asd/>.

Podcast: Supporting the mental health of parents: Opportunities for intervention

This episode of the Centre for Research Excellence-Cerebral Palsy (CRE-CP) podcast focuses on the mental health care needs of parents of children with a disability. The talk highlights research findings on the barriers for mothers in accessing support for their mental health, and their preferences for support from the child health and disability service system. Professionals' experiences in supporting mothers' mental health is also addressed, along with opportunities to better support mothers' mental health from the individual level to the broader service system.

Access the episode directly at www.cre-cp.org.au/education-training/podcasts/ or subscribe to the podcast by searching "CRE-CP" in any podcast app.



Research Update

Stem Cells in Umbilical Blood Infusion for Cerebral Palsy (SCUBI-CP)

Australia's first clinical trial of stem cell infusion as a treatment for CP started in March 2016. The trial is small and aims to find out whether cord blood stem cell infusion is safe for children with CP. This study is made possible by the generous support of Cerebral Palsy Alliance and Cell Care Australia Pty Ltd.

The clinical trial team are looking for children with CP who have a brother or sister who has cord blood in storage from their birth. Only around a quarter of brothers and sisters have blood that matches, so the doctors in the trial will test the children's blood to look for a match. The trial will involve a number of hospital visits over a 14 month period.

They are looking for about 12 children to be in the trial, across Australia. If you would like more information about this trial please contact the study coordinator at scubi.cp@mcri.edu.au.

Bike riding skills for children with cerebral palsy

The Bike Skills project is led by physiotherapist and PhD candidate Rachel Toovey. The overall aim of this project is to develop and test ways of training two-wheel bike riding skills in children with CP. The first part of this project was a study looking at two-wheel bike riding ability in children with and without CP. Thanks again to all the parents and caregivers who completed this survey last year. A summary of results for respondents will be coming soon. Rachel has presented the results at the Australasian Academy of Cerebral Palsy and Developmental Medicine in Adelaide in March and at the International Cerebral Palsy Conference in Stockholm, Sweden in June this year.

The project is currently focused on finding out about the ways therapists across Australia currently train bike riding in children with CP and putting together the relevant research to develop evidence-based ways to train these types of skills. We are also planning a study that will test these ways of training bike skills. This study will be recruiting children with CP and their families who have goals related to training two wheel bike riding skills later in the year. For more information on the project, please contact rachel.toovey@mcri.edu.au or visit <http://www.cre-cp.org.au/research/current/bike-riding/>.

Hip Surveillance Project Update

Parent and carers of Victorian children with CP were recently invited to participate in a research project exploring their experiences of hip surveillance. The project was undertaken through the Centre of Research Excellence in Cerebral Palsy (CRE-CP). We received a wonderful response to the project and sincerely thank everyone who expressed interest participating. Twenty-three parents and carers were able to participate in the study which was conducted through a combination of face-to-face focus groups and teleconferences that allowed parents from regional and rural areas to participate.

The discussion provided an opportunity for parents and carers to share their experiences of how hip surveillance happens for their child, and factors that make the process either easier or challenging. The findings will be analysed alongside the results of a survey of health professionals that took place last year and explored their current practices of hip surveillance in Victoria. This will allow us to understand the unique experiences of both parents and health professionals in engaging in the hip surveillance process and assist in the development of family-oriented processes for a state-wide program for hip surveillance. If you are interested in finding out more about the Hip Surveillance Project, visit <http://www.cre-cp.org.au/research/current/hip-surveillance>.

Community Coordinator position

The Centre for Research Excellence-Cerebral Palsy (CRE-CP) will be hiring a Community Coordinator to lead the implementation of community engagement in all aspects of the research program. This is an exciting development for the CRE-CP and a unique opportunity for the right candidate to lead a new approach to effective community engagement. They are looking for someone with a personal connection to cerebral palsy. This could be an adult with cerebral palsy, or a parent, sibling or other relative of somebody with the condition.

The Community Coordinator will have four main roles:

- Establish and maintain a community discussion forum
- Match interested community members to be involved with research projects
- Champion community engagement in all aspects of the CRE-CP
- Develop a 'lessons learned' document on community engagement

The position will be for one day per week (with flexible hours). It will be based in Melbourne and advertised in late July; please check the CRE-CP website at that time for more information: www.cre-cp.org.au.



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