

Melbourne Magic!

Children with hemiplegic CP can have difficulty with everyday tasks that require the use of two hands. The Amazing Magic Club is a new approach to bimanual therapy. In April 2015, 12 children from the VCPR participated in Melbourne's first Amazing Magic Club, thanks to the Arts Health Institute who has brought this innovative program, which was developed by the UK's Breathe Arts Research, to Australia. This was organised by Ms Ashleigh Hines, an Occupational Therapist based at the University of Sydney, as part of her PhD research.

For ten days over the school holidays, the children embarked on an intensive program to encourage the use of two hands in every activity, from practicing magic tricks, to eating lunch with a knife and fork, to craft sessions in the afternoon where the children sewed their own magician costumes and decorated magic hats and wands. At the end of the two weeks, to showcase their new skills, the children put on a performance in front of a sell out audience of family and friends at Theatre Works in St Kilda. Thank you to all the children and their families who participated in this project, pictured below. For more information on the Arts Health Institute's Amazing Magic Club, or to register your interest for a future Amazing Magic Club, please visit the website <http://www.amazingmagicclub.org.au>.



Follow up of children on the VCPR

We are continuing with our long-term project which involves following up children registered with the VCPR as they grow. After they turn 5, 10 or 15 years of age, children will be invited to have a short assessment with a physiotherapist at the Royal Children's Hospital. We want to understand if changes occur in children's ability to move, communicate or complete everyday activities as they get older. Findings may guide future important CP research.

To date, around 200 children have had an assessment with a physiotherapist as part of this project. Look out for your child's invitation to participate in this project around the time of their fifth, tenth, or fifteenth birthday. We are very grateful to the Victorian Medical Insurance Agency for funding this project.

You can read about our research on the Developmental Disability and Rehabilitation Research Group's page on the Murdoch Childrens Research Institute website: <https://www.mcri.edu.au/research/themes/clinical-sciences/developmental-disability-and-rehabilitation-research>.



This year, the focus of World Cerebral Palsy Day will be on **Social Change**. The aim is to shine a spotlight on the most important issues for people with CP and their families around the world, and drive action. You can find out more about World Cerebral Palsy Day 2015 by visiting the website: <http://en.worldcpday.org/about/>.

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If you would like to receive future newsletters and other VCPR correspondence by email, please let us know by sending an email to the above email address.



VCPR news



June, 2015

Welcome to the 8th newsletter of the Victorian Cerebral Palsy Register (VCPR). There are now **5,300 individuals** (registered with the VCPR. This makes it one of the largest cerebral palsy (CP) registers in the world. We greatly appreciate the involvement of individuals with CP and their families - without them, much of the work we do would not be possible. As always, if you have any questions or concerns, or if we can be of any assistance, please get in touch. You will find all of our contact details at the end of this newsletter.

Some highlights of the past six months include:

- Representatives of the CP registers for each of the other Australian states attended a meeting which we hosted here in Melbourne earlier this year. Each state's CP register operates independently, but researchers from each register collaborate to form the **Australian Cerebral Palsy Register (ACPR)**. The ACPR group meets regularly to discuss current issues in CP research, and they work together on various projects. The next report of the ACPR will be published in 2016. You can view the last report online: <https://www.cerebralpalsy.org.au/timeposts/the-australian-cerebral-palsy-register-report-2013/>.
- We have created a new **webpage** where you can find general information on CP, as well as information on some of our research projects: <https://www.mcri.edu.au/research/projects/victorian-cerebral-palsy-register>.
- We have started a new process whereby when individuals registered with the VCPR turn 18 years of age, we will ask their parent/carer if we should begin communicating (e.g. with newsletters and research invitations) with the young person directly, rather than with their parent/carer. Of course, in many cases, it will be more appropriate to continue communicating with the parent/carer directly, and in these cases, we will continue to do so. However, we feel that it is important to provide young people who are able to **self-consent** with the opportunity to decide for themselves if they want to continue their involvement with the VCPR.
- We have been involved in a number of interesting **research** projects, some of which you can read more about in this newsletter.
- We recently welcomed a new staff member. Charmaine Bernie is an Occupational Therapist, and is looking forward to working on some exciting CP research projects with our team.

CP FACTS: Families | Activities | Child-care | Tips | Seminars

When: 10am – 2pm, Sunday 9th August, 2015

Where: Darebin Arts & Entertainment Centre, Corner Bell Street & St. Georges Road, Preston, VIC 3072

The Centre of Research Excellence in Cerebral Palsy (CRE-CP) and the Cerebral Palsy Support Network (CPSN) are excited to be working together on CP FACTS - a **free half day family event** designed to provide reliable information related to CP. Information will be made available through presentations, seminars, exhibitions and stands. There will be ample opportunity to speak directly with exhibitors, researchers and support organisations to ask all those questions you would like answered. In addition, kids will be entertained with a range of games and activities, making it a day the whole family can enjoy. Activities such as magic shows, face painting, film screenings, games and entertainment will cater for children of all ages and abilities. Lunch and healthy snacks will be provided.

This event is free but registration is required. Please visit <http://www.cre-cp.org.au/cpfacts/> for details on how to register. You can also email cre.cp@mcri.edu.au or phone (03) 9936 6087 for further information.

You can find out more about the CRE-CP and sign-up to the newsletter on their website: <http://www.cre-cp.org.au/>. You can also keep up-to-date by following the CRE-CP on twitter @CRE_CP. To find out more about the services the CPSN offers, you can visit their website <http://www.cpsn.org.au/>, or call 1300 277 600.



Victorian State-wide Hip Surveillance Project

The State-wide Hip Surveillance Project is led by physiotherapists Kate Willoughby and Rachel Toovey within the Centre for Research Excellence in Cerebral Palsy. Hip Surveillance is the process of regular x-rays to detect and monitor hip displacement, a condition that occurs commonly among children with CP. Hip displacement refers to the 'ball' of the hip joint moving slowly out of the 'socket'. If not treated early and effectively it can lead to painful hip dislocation. Hip surveillance is vital for detecting hip problems early in life when treatment is most effective. **This project aims to develop a state-wide program for hip surveillance for all Victorian children with cerebral palsy.** The aim is for the program to include processes to enable routine hip surveillance, implement ways to remind families and health professionals when x-rays are due, and identify avenues for follow-up when children do not receive surveillance in a timely manner. In addition, it is hoped that all of these processes will be efficient, sustainable and well-accepted by both families and health professionals.

Family and health professional involvement is a key part of the project, through opportunities such as focus groups and surveys. Earlier this year, Victorian health professionals were invited to complete an online survey about current hip surveillance practices in the state, and we asked them to identify challenges that may currently exist and current practices which make hip surveillance easier. The survey responses are currently being analysed and will help to develop the hip surveillance service for Victoria. The perspective and experiences of parents and carers of young people with CP will also be vital to the project and studies involving parents and carers are currently being planned. Please visit the hip surveillance page of the CRE-CP website (<http://www.cre-cp.org.au/research/current/hip-surveillance>) for more information about this work, and information about how you can be involved.



Research update

Stem cell research in cerebral palsy - where are we up to?

A small Australian trial of umbilical cord blood cells for children with CP is waiting for final approval from the Royal Children's Hospital's Human Research Ethics Committee. Once the last details have been worked out, the trial may begin. This may occur later this year. Children with CP who have either their own, or a sibling's, cord blood stored from birth may be eligible to participate. Information about the trial will come through CP Registers, community and professional organisations, and private cord blood banks.

Dr. Kylie Crompton from Murdoch Childrens Research Institute, is currently coordinating this project, which involves researchers and clinicians from around Australia. Kylie recently wrote a blog post on the ethical issues that surround stem cell research in children with CP which you can read online: <https://www.mcri.edu.au/users/dr-kylie-crompton/blog/stem-cell-research-cerebral-palsy-ethical-implications>. The Australasian Faculty of Rehabilitation Medicine published a Position Statement on the use of stem cells as a therapy for CP in November 2014: <https://www.racp.edu.au/index.cfm?objectid=02A28582-E795-54CF-2A8041E0BD658E1E>.

For further information, please contact Kylie by phone: (03) 9936 6756, or email: kylie.crompton@mcri.edu.au.

Understanding the causes of cerebral palsy

Considering CP is the most common physical disability of childhood, it's really surprising that so little is understood about why CP happens in some cases but not in others. Part of the reason is that each child with CP is unique and their pathway through life as a tiny ball of cells, a fetus, a neonate, and an infant may have been very different from other children with CP. In order to study causal pathways we need to include a large cohort of children with CP, so we can divide them into groups that are more alike. For this study we are grouping children according to the main patterns of abnormality on their brain scans. Within each group we will look at a variety of maternal, pregnancy, birth, and neonatal factors that might help us better understand the causal pathways. We hope that this may ultimately lead to the discovery of new risk factors that may help prevent some cases of CP in the future.

The study involves completing a maternal questionnaire which can be done in paper form or online, providing optional consent to access birth information and brain scans, and providing an optional saliva sample from the child (we send a kit). We are inviting birth mothers to participate in the study if their child was born in Victoria between 1999 and 2008 and there are brain scans available that show one of four main patterns of injury (normal scans and some miscellaneous findings are not included at this time). Thank you to the 134 mothers who have already completed the survey. If you think you are eligible and would like to participate, we would be most grateful for your contribution; however, we understand that it may be difficult to re-visit these issues.

For further information, please contact Angela Guzys: (03) 9936 6089 / angela.guzys@mcri.edu.au, or Sue Reid: (03) 9345 4807 / sue.reid@mcri.edu.au.

Recent research projects

Bicycle skills project

The bicycle skills project is led by physiotherapist Rachel Toovey, pictured left with Viv. This project is exploring whether learning to ride a bike can be a way to improve physical activity and overall health in children with CP, as in general, children with CP do less recreational and physical activities than children without CP.

Many parents would have recently received an invitation to participate in an online survey, the first study as part of this project. This study was undertaken as part of Rachel's Master of Public Health and Tropical Medicine and is supported by the VCPR. The invitation was sent to parents of children with and without cerebral palsy aged 6-15 years who are able to walk without aids. The survey asked parents about their child's ability to ride a two wheel bike, the age at which they learnt, if at all, and what parents believe help children learn to ride a bike and what the difficulties may be. The survey closed at the end of May.

Thank you to all parents and carers who completed the survey. Results are currently being analysed and will be available in the second half of 2015. There will be future opportunities for families of children with CP to be involved in this project.

Please visit the bike skill project website <http://www.cre-cp.org.au/research/current/bike-riding/> for more details and to sign up to the project mailing list.



Genetic and epigenetic studies in cerebral palsy

Researchers from our team are working together with world experts as part of the Cerebral Palsy Genetic Research Network, to study genetic risk factors for CP in individuals who do not have a known cause for their CP and have normal brain imaging. By working with an international group, we hope to see patterns in genetic differences in individuals with CP that would not have been noticeable otherwise. We do not expect that these genetic differences are passed from parents to child, they are probably new changes.



They are also studying the epigenetic ('above genetic') risk factors for CP, working with A/Prof Jeff Craig from Murdoch Childrens Research Institute. They are looking for changes around DNA that control how genes are expressed. Epigenetic changes happen all the time as our environment changes and our bodies need to respond. For this reason, identical twins who have the same genes and almost the same environment before birth (but only one of the pair has CP) allow us to look for changes that might be related to CP.

We would like to thank all the families who are participating in these studies. We look forward to sharing the results with you as soon as they are available. For further information, please contact Kylie by phone: (03) 9936 6756, or email: kylie.crompton@mcri.edu.au.

Health Services Research

Health services research is an area of research that examines how people get access to health care services, how much care costs, and what happens to patients as a result of this care. As part of her PhD research, Elaine Meehan is investigating the use of health services among children and young people with CP. To date, she has looked at hospital admissions and emergency department (ED) presentations to the Royal Children's Hospital, Melbourne and Monash Children's Hospital. She found that between 2008 and 2012, children and young people with CP aged 5-19 years had a total of 7,177 admissions and 3,631 ED presentations to Victoria's two specialist paediatric hospitals. Respiratory illnesses were the most commonly reported reason for hospital admissions and ED presentations in this group.

One paper based on this research has been published in the medical journal, the Journal of Paediatrics and Child Health, and another in Child: Care, Health and Development. The results were presented at the conference of the Australasian College for Emergency Medicine which was held in Melbourne in December last year, and Elaine will be giving an oral presentation based on this research at the annual conference of the American Academy for Cerebral Palsy and Developmental Medicine which is being held in Austin, Texas later this year. For further information on this research, please contact Elaine by phone: (03) 9345 4808, or email: elaine.meehan@mcri.edu.au.