

CP Register

Victoria



Issue no. 5

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Welcome to the fifth 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 some of our progress to date and highlights some of the recent findings that have come from our research. We have been involved in lots of research projects over the past 6 months and have many new projects coming up in the near future.

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



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World Cerebral Palsy Day 2013

The Department of Developmental Medicine and the VCPR celebrated World CP Day at the Royal Children's Hospital on Thursday, October 3rd 2013. World CP Day is a global project that aims to change the world for people living with CP. It is designed to gather ideas from people around the world and make the best of those ideas a reality.

We celebrated the day by having a host of fun activities throughout the hospital including face-painters and a petting zoo! We also had an "Ideas Box" set up where children and their families could post their ideas for something that could change their lives for the better. The day was a huge success and thoroughly enjoyed by patients, families and staff!



**WORLD
CEREBRAL
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DAY**
02.OCT.2013

An update on our progress to date

The VCPR now holds information on 5100 individuals with cerebral palsy (CP) who were born since 1970. The majority were born in Victoria and the rest have moved to Victoria from another state or overseas. It is fantastic that half the families of individuals 18 years or younger have now consented to be contacted by the VCPR for research studies. We are very grateful for the incredible response we get from families to invitations to participate in research.

To date, 64 papers involving the Victorian Register have been published in medical journals. Since our previous newsletter, presentations have been made on brain MRI findings in CP at the International Congress of Pediatrics, the Australian Physiotherapy Association Conference, and the Annual Meeting of the American Academy for Cerebral Palsy in Milwaukee, USA. In Milwaukee, we also ran an instructional course on issues relating to saliva control. More locally, Dinah Reddihough and Sue Reid both gave talks on the Register and on some of our research projects at Scope in Box Hill and at Kids Plus in Geelong.

Sixteen PhD students have used the VCPR for their projects and 13 of these have now completed their PhDs. Elaine Meehan, the research assistant working with the VCPR, is continuing to work on her PhD project on access, affordability and quality of health care for children with CP. Speech pathologist Cristina Mei is about to submit her PhD thesis on communication skills in children with CP.

Follow-up of children on the VCPR

Last year, we started to follow-up children on the Register as they turned five, ten or fifteen years of age. This involved contacting children soon after they turned five, ten or fifteen, and inviting them to have an assessment with a physiotherapist and an occupational therapist at the Royal Children's Hospital.

Our aim is to collect important information on each child's abilities and to monitor changes in their movement disorder as they grow up. To date, we have carried out these assessments on 105 children. We are grateful to the Victorian Medical Insurance Agency for funding this project. Please look out for your child's invitation to participate in this research in the mail as they turn five, ten or fifteen!

Below is a picture of Lyla Devaney taken at the Royal Children's Hospital in celebration of World CP Day. Lyla's 1st birthday fell on World CP Day this year!



Future Research

We have a number of exciting new research studies starting soon!

• Health services research:

Elaine Meehan is looking at the health services needs of children and young people with CP as part of her PhD research. She will be asking parents to complete an online, telephone or postal survey on the types of medical professionals their child sees. This research is important for future health service planning for children with CP.



• MRI findings in CP:

We are grateful to have obtained funding support from both the Ian Potter Foundation and the National Health and Medical Research Council for a new study on MRI findings and causes of CP. This study will be led by Sue Reid and will include children with CP who were born in Victoria between 1999 and 2008. Invitations to participate in this exciting study will be posted out to families some time during 2014.

You may receive invitations to take part in these research projects in the mail over the coming months. We would really appreciate you taking the time to read the information and considering taking part in these important pieces of research.

Therapy Services Research

Last year, 86 parents of children with CP completed a survey on the types of therapy their child receives. We found:

- 83% of children had received occupational therapy, 88% had received physiotherapy and 60% had received speech and language pathology over the previous year
- Children with more severe CP received more therapy than children with mild CP
- Children attending special schools received more therapy than those attending mainstream schools
- Young children receive more funding for therapy than older children
- 40% of parents were dis-satisfied with the amount of therapy their child had received in the past year

This information may be useful for policy makers with the impending roll-out of the National Disability Insurance Scheme.

A Centre for Research Excellence in Cerebral Palsy

It is wonderful news that Dinah Reddihough and her team have been awarded a grant from the National Health and Medical Research Council to set up an Australian Centre for Research Excellence in CP. The Centre will have a significant impact on the care of individuals with CP.

What work will the Centre do?

The purpose of the Centre is to bring together leading researchers in Australia to produce a significant improvement in the treatment of young people with CP. Specific aims are to improve functional abilities, participation and quality of life. These goals will be accomplished by:



- introducing regular check-ups for all children with CP (and some children are already receiving these checks through the CP check up: providing the best service at the best time project)
- undertaking more research to determine the best treatments and by determining better ways to assist families

Currently the number of researchers working in the area of CP is small. The Centre will address this problem by providing training scholarships to increase the research workforce. The knowledge generated will be made available to parents and to those working with individuals with cerebral palsy.

What can you do to help?

Parents know more about children with CP than anyone else. We would like the involvement of families in some of the working groups that will generate research questions and outline the work that is to be done. If you are interested, please contact us at vic.cpregister@rch.org.au

Stem Cell Research in Cerebral Palsy

Over the past year, researchers at the Murdoch Childrens Research Institute have looked at a range of options to test cord blood stem cell therapy for children with CP. The cells for this therapy would ideally come from a child's own cord blood that was stored at their birth, because their body will recognise the cells as safe. Unfortunately, a lot of children with CP have difficult or preterm births, and no cord blood can be collected and stored. The next safest option is to find out if cells from a brother or sister's cord blood are a match, and another option is to search for a good match with cord blood cells from an unrelated donor. This last option would be open to anyone, but it can be difficult to find a good match, and currently Australia's public cord blood banks are not licensed to release stored cord blood for this type of research.

What are we doing now?

Researchers in Melbourne, Sydney and Brisbane are now working together to plan trials looking at the role of stem cells in children with CP in Australia. They hope to run a small pilot trial later next year with around 20 children who have CP and who also have either their own or a sibling's cord blood in storage.

If you would like further information on this research, please contact the stem cell research co-ordinator Dr. Kylie Crompton on 03 9936 6756 or email kylie.crompton@mcri.edu.au



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