

myHealthRecord: The Australian Personally Controlled Electronic Health Record (PCEHR)

Young adults with cerebral palsy often struggle to communicate their personal health information to health service providers. This may result in poor care.

This project will examine the views, needs, and experiences of young adults cerebral palsy and communication difficulties on their preferences regarding how they keep and use personal health information, and any barriers to or strategies for enabling access to the PCEHR. Young adults and their families can take part from anywhere in Australia if they have Internet access.

For further information, or if you would like to participate, please contact Bronwyn by telephone or email.

T: (02) 4921 7352

E: bronwyn.hemsley@newcastle.edu.au



The graphic features the University of Newcastle Australia logo, a photo of a family, and the hashtag #myHealthRecord. It includes the text: 'myHealth' A personal electronic health record (PCEHR) for people with Cerebral Palsy or Autism or Intellectual Disability. We would like to talk to young people (16 – 21yrs) with communication difficulties and their families/ support workers. How will you use e-health records? Contact: bronwyn.hemsley@newcastle.edu.au www.surveymonkey.com/ehealthrecords

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 or occupational therapist at the Royal Children's Hospital, Melbourne. 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, 217 children have had an assessment with a physiotherapist or occupational therapist 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.



For World Cerebral Palsy Day this year, we published a number of blog posts related to cerebral palsy on the Murdoch Childrens Research Institute blog, Impact, and shared them widely on social media.

You can read them online by following this link:

W: [https://www.mcri.edu.au/blogs?f\[0\]=im_field_keywords%3A1475](https://www.mcri.edu.au/blogs?f[0]=im_field_keywords%3A1475)

The Victorian Cerebral Palsy Register,
Developmental Disability and Rehabilitation Research,
Murdoch Childrens Research Institute,
Royal Children's Hospital,
50 Flemington Road,
Parkville, Vic 3052



T: Elaine (03) 9345 4808 or Sue (03) 9345 4807

E: vic.cpreregister@rch.org.au

W: <https://www.mcri.edu.au/research/projects/victorian-cerebral-palsy-register>

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



December, 2015

Welcome to the 9th newsletter of the Victorian Cerebral Palsy Register (VCPR)!

There are now **5,473 individuals** registered with the VCPR, and to date 83 different research studies that have involved the VCPR have been carried out. This has resulted in a total of 93 publications in medical journals. We greatly appreciate the involvement of individuals with cerebral palsy and their families - without them, much of this work would not have been 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:

- A number of researchers from our team recently attended the annual conference of the American Academy for Cerebral Palsy and Developmental Medicine (AACPDM) which was held in Austin, Texas. This year, the theme of the conference was "New Frontiers", and clinicians and researchers from around the world came together to present and discuss the current state-of-the-art science in cerebral palsy and other childhood-onset disabilities. Sue and Elaine from the VCPR team gave a total of four presentations. Topics of their presentations included trends in the rates and severity of cerebral palsy over time, brain imaging characteristics and hospital admissions in children and young people with cerebral palsy.
- We welcomed a new team member - Debbie Cations is helping out with the VCPR follow-up study (more information about this on the back page).

The VCPR team would like to wish you and your family a Happy Christmas and all the best for 2016!



Looking for new members for our advisory committee

The VCPR has an advisory committee that meets at least once each year to review the progress of the Register and provide general oversight and guidance about how it operates. We are inviting parents/carers of children with cerebral palsy as well as adults with cerebral palsy to join our current committee. Membership of the committee would involve one face-to-face meeting (held at the Royal Children's Hospital, Melbourne) per year and occasional email or telephone contact. The next meeting will be held mid-late 2016.

If you would like to join and have an input into how the VCPR operates going forward, please contact us by phone or email.

T: Elaine (03) 9345 4808 | Sue (03) 9345 4807

E: vic.cpreregister@rch.org.au



Research update

Understanding the causes of cerebral palsy

For many individuals, the cause of their cerebral palsy remains unknown despite extensive testing, and there is still a lot to learn about why cerebral palsy happens in some cases but not in others. The study, led by Dr Sue Reid (pictured below), involves asking birth mothers of children with cerebral palsy to complete a questionnaire on their pregnancy and the birth and early life of their child with cerebral palsy. This can be completed online or via paper copy. We are also asking parents to provide optional consent to access birth information and brain scans, and to provide an optional saliva sample from the child (we send a kit).

We are inviting 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).

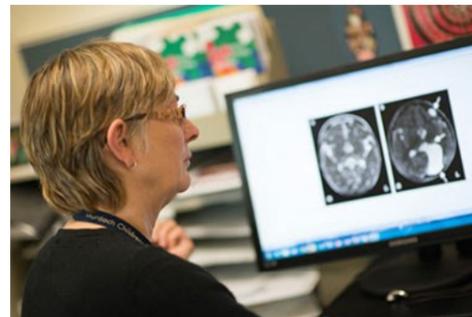
Thank you to the 191 mothers that have already completed the questionnaire. A further 59 mothers have been sent the online link or a paper copy to complete at home—if you are one of these families, it's not too late to send your questionnaire back to the research team.

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 or Sue by telephone or email.

T: Angela Guzys: (03) 9936 6089 | Sue Reid: (03) 9345 4807

E: angela.guzys@mcri.edu.au | sue.reid@mcri.edu.au



Medical care needs of children and young people with cerebral palsy

Earlier this year, we invited the parents and carers of children and young people with cerebral palsy to complete a survey on their child's use of various medical services. We asked parents about appointments their child had with general practitioners (GPs) and public and private paediatric medical specialist over the previous 12 months.

- 350 parents and carers completed the survey. Of these, 51% had a child with a mild motor impairment, while 48% had a child who had a moderate or severe motor impairment.
- 83% of children had at least one appointment with a GP over the previous 12 months, while 84% had at least one appointment with a public or private paediatric medical specialist.
- 58% of children had appointments with between two and five different specialists, while 9% had appointments with six or more different specialists over the previous year. Older children and adolescents continued to see a number of different medical specialists.
- 34% of parents reported that their child's medical issues had caused financial problems for their family. The parents and carers of children with more severe cerebral palsy were more likely to have experienced such financial difficulties.

The results of this research have recently been accepted for publication in the *Journal of Paediatrics and Child Health* which is the official journal of the Paediatrics and Child Health Division of the Royal Australasian College of Physicians. It is hoped that the information will be useful for parents and medical professionals involved in the care of children and young people with cerebral palsy by highlighting the types of medical services required by children with cerebral palsy and confirming that their need for multiple specialist medical services don't "disappear" when a child reaches adulthood.

If you would like any further information, please contact Elaine by email:

E: elaine.meehan@mcri.edu.au

Quality of life study for children with learning difficulties

Researchers in Western Australia are working to better understand quality of life for children with learning difficulties, including some children with cerebral palsy. This study is identifying important aspects of life and will then develop a parent-report measure of the child's quality of life. The new measure will be useful to identify what supports the children might need and to test the effectiveness of clinical treatments.

Families who have a school-aged child with cerebral palsy and some learning difficulties, and are registered with the VCPR are being invited to participate. Ten interviews have been completed and so we are about half way through collecting data for this study. We wish to thank these families for their enormous help.

Parents' insights into the importance of aspects of their child's day to day life are invaluable by providing a voice about their child's happiness and wellbeing. Some of this information is already being analysed and we look forward to sharing more on the new measure in the near future.

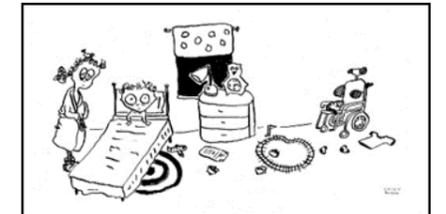
For more information on this study, contact Dr Jenny Downs by telephone or email.

T: (08) 9489 7777 | E: jenny.downs@telethonkids.org.au

Bed time stories: An exploratory study of sleep disturbance for children with cerebral palsy

Sacha Petersen, a nurse consultant with the Department of Developmental Medicine at the Royal Children's Hospital, has a background in neuroscience nursing and has spent the last ten years as an advance practice nurse for children with intrathecal baclofen pumps (many of these children have cerebral palsy). Sacha noticed many of her patients had significant sleep issues, but sleep is often overlooked and not discussed in clinic appointments.

Sacha conducted a small pilot study in 2014 to explore sleep problems for children with cerebral palsy. This study revealed that getting useful information about sleep for children with cerebral palsy and their parents is tricky and that more research is needed. Sacha commenced a PhD in March 2015. The main aim of her PhD research is to develop an intervention to improve sleep for children with cerebral palsy and their parents.



Sacha will be inviting families registered with the VCPR to participate in this research project in 2016. She plans to survey the parents of children aged between 6 and 12 years to ask them about their experience of sleep, good or bad. Watch this space!

Bike Skills Project update: a report from abroad

What initially begun as a Masters-level project, the bike skills project is now being undertaken as a PhD by physiotherapist, Rachel Toovey. Rachel's PhD will focus on developing bike skills programs for children with cerebral palsy. Rachel was recently awarded a Felice Rosemary Lloyd Physiotherapy Travel Scholarship enabling her to spend 4 weeks in October visiting expert researchers and clinicians in the areas of motor learning, task specific training and cerebral palsy.

Rachel's first stop was to the Netherlands, home of bike riding culture. Here she learnt about measuring changes in the physical activity kids do from the team at De Hoogstraat Rehabilitation Centre in Utrecht and learnt about different ways kids learn movement skills at Radboud University in Nijmegen. This was followed by a visit to the Sports for Brains organisation in Copenhagen, Denmark. Rachel then hopped continents and ended up in Austin, Texas for the American Academy of Cerebral Palsy and Developmental Medicine Conference. Rachel also spent some time with the team at CanChild – Canadian Childhood Disability Research Institute and learnt about how to do research well. Last but not least, Rachel visited Virginia Wright at the Holland Bloorview Kids Rehab Hospital in Toronto. Virginia is an expert in how kids with cerebral palsy learn to move. She will be presenting a special seminar for the Centre for Research Excellence in Cerebral Palsy in April 2016 - keep your eyes peeled for more information.

Thanks to everyone who participated in the survey "Bike riding ability for children with and without cerebral palsy." A results summary will be sent to you shortly. You can find out more about Rachel's PhD and the Bike Skills Project at <http://www.cre-cp.org.au/research/current/bike-riding/>.