Welcome to our NSW/ACT CP Register Newsletter, December 2019 edition. Our aim is to provide you with updates and news from the NSW/ACT CP Register, information on studies taking place and their findings when completed. If you have any suggestions for upcoming newsletters, please contact us.

Best wishes!

Sarah, Hayley, Shona, Katarina, Emma and Isabelle

I. Latest News

Coco and the Cockatoos

Coco and the Cockatoos are excited about their new album ‘Wild Life’ which has ten unique songs about animals from all over the world.

All songs are written by ten-year old Sydney schoolgirl Coco Espie and singer/songwriter Jane Walker. Coco has cerebral palsy, album sales will contribute to Sydney Children’s Hospitals Foundation, which helps many sick kids.

The songs celebrate different animals, so sales also contribute to Taronga Conservation Society Australia and Ocean Recovery Alliance.

[Click here to listen to an extract](#) and enjoy the music!
The Little Readers Read-a-thon a great success.

The Little Readers Read-a-thon took place during September 2019 across 21 Neonatal Intensive Care Units (NICUs) across the world and led by the Grace Centre for Newborn Care, the Children’s Hospital at Westmead. The initiative aims to empower parents to read to their baby every day during their stay in the NICU. Not only does reading support infant development, it aims to support families during a stressful period through the comfort a baby experiences listening to their parents’ voice. This year’s event was a great success with a special appearance from celebrity and children’s author Kate Ritchie.

Researchers from The University of Western Australia have developed an online risk calculator for respiratory illness for children and young people with cerebral palsy. The checklist is based on extensive research conducted in Western Australia and can be completed in less than 5 minutes by parents, people with cerebral palsy or with clinicians. It helps identify risk factors which can indicate a greater risk of respiratory disease. It aims to provide general advice designed to empower individuals with cerebral palsy and their families to work with health professionals to minimise respiratory illness.

Click here to complete the checklist
II. Current Research - Seeking participants!

1. Stem cell survey

Sharing your experience of overseas stem cell treatment for cerebral palsy

Researchers from the Cerebral Palsy Alliance Research Institute are conducting an online research survey to understand the experiences of those who have travelled overseas for stem cells. They want to gather information on the considerations, costs, impact and potential outcomes of this travel and treatment.

Who can participate?

- Individuals with cerebral palsy or their carer/parent/sibling who travelled outside their country of residence for stem cell treatment/s
- Stem cell therapy was received specifically for treatment of cerebral palsy
- Stem cell therapy was not a part of a clinical trial

What's involved?

This survey is conducted online and will take approximately 20 minutes to complete.

Click here to take the survey

For more information about this study please contact Dr Madison Paton at CPA.
Tel: 02 8052 2058 Email: madison.paton@cerebralpalsy.org.au
2. Participate CP

Optimising Participation in Physically Active Leisure for Children with Cerebral Palsy.

Children and young people with cerebral palsy participate less often in sports and physical activities than their peers without cerebral palsy. We've designed a different type of program delivered by a physiotherapist, occupational therapist or exercise physiologist that aims to get kids with cerebral palsy to engage in sports and physical activities that are meaningful to them.

The new program respects barriers (things that get in the way) to your child’s participation, but also their strengths and individuality. The program is designed to suit your family circumstances and unique situation.

Who can participate?

Children with cerebral palsy (GMFCS Levels I-IV) 8 to 14 years old living in greater Sydney area.

What’s involved?

- 1 hour per week face-to-face therapy for 12 weeks Delivered by physiotherapists and occupational therapists
- Partnering with you and your child to achieve goals about participating in sports and physical activities
- Guiding you to create solutions to problems you face when trying to help your child be more physically active
- Linking you up with the tools and information you need
- Delivered in your home and places where sports happen in your local community

For more information about this study please contact

Emma Stanton at CPA.
Tel: 02 4736 8722   Email: estanton@cerebralpalsy.org.au
3. MUGgLE

Muscle growth in children with and without cerebral palsy.

A team of researchers from Neuroscience Research Australia (NeuRA), The Cerebral Palsy Alliance Research Institute, and the University of New South Wales, with assistance from health professionals at the Sydney Children’s Hospitals Network are investigating how muscle growth in children with cerebral palsy differs from muscle growth in children without cerebral palsy.

Who can participate?

Babies aged from birth to approximately 3 months and children aged from 5-15 years. Children with and without cerebral palsy are eligible to participate.

What’s involved?

If your child is a baby (less than four months old), participation in the study would require attending Neuroscience Research Australia (NeuRA) in Randwick on just one occasion.

If your child is aged 5 years or over, participation in the study would require attending Neuroscience Research Australia (NeuRA) in Randwick on three occasions over three years. Visits can occur after school, or on Saturdays, or during school holidays.

For more information about this study and to participate please contact the Principal Investigator Professor Rob Herbert at NeuRa.

Tel: 02 9399 1833    Email: r.herbert@neura.edu.au
4. HABIT-ILE

Hand Arm Bimanual Intensive Training Including Lower Extremity.

Children and adolescents with cerebral palsy can find it difficult to use their two hands together to do everyday activities. They can also have trouble with their gross motor skills and how they move around. We are testing an intensive type of therapy called Hand Arm Bimanual Intensive training Including Lower Extremity Training (HABIT-ILE) delivered by physiotherapists, occupational therapists and therapy students to help kids improve their motor skills and independence in daily life activities.

Who can participate?

Children with bilateral cerebral palsy (GMFCS II-IV) aged 6-16 years living in Western Sydney area.

What's involved?

- Training 6.5 hours/day for 10 weekdays during 2 weeks of school holidays
- Groups will include 10-12 kids
- Delivered by physiotherapists, occupational therapists and therapy students
- 1-on-1 therapy with a dedicated therapist
- Using play, craft, cooking, everyday living skills and gaming technologies
- Personalised to your child's goals, priorities and interests

HABIT-ILE research camps will run in July 2020 and January 2021 school holidays, at Cerebral Palsy Alliance in Prairiewood, NSW.

For more information about this study please contact Ashleigh Hines. Tel: 02 8777 1777 Email: ahines@cerebralpalsy.org.au
5. Body composition

Body Composition of Adults with Cerebral Palsy

Researchers from the University of Sydney are looking at the relationship between physical activity level, body composition (including bone density, body fat percentage and muscle mass) and strength in adults with cerebral palsy.

Who can participate?

Adults aged 18-65 years with cerebral palsy who are able to walk on level ground either with or without walking aids (GMFCS I-III). People with a variety of physical activity levels, from those who do no activity at all up to competitive athletes.

What’s involved?

A one-off assessment at The University of Sydney, Cumberland Campus, Lidcombe. Participants will receive a free DXA scan and report on the amount of bone, muscle and fat in their body, waist girth and measures of muscle strength, at no cost.

For more information about this study please contact Jennifer Fleeton.

Tel: 0417 435 060      Email: jennifer.fleeton@sydney.edu.au
III. Future Projects and Events

1. **Financial cost of living with CP**

   The financial cost of cerebral palsy when living in Australia.

   This comprehensive questionnaire will aim to determine the out of pocket costs and financial distress for families and people living with cerebral palsy across severity and age groups in Australia. The report from this study will provide a voice to the families and people living with cerebral palsy to better inform policy and decision makers about their financial stress. The researchers (including 3 CP Quest members) are currently reviewing the survey questions, study protocol and applying for ethics approval. **Recruiting early 2020**

2. **VISIBLE**

   **Vision Intervention for Seeing Impaired Babies: Learning through Enrichment.**

   This project includes families of infants with brain injury that occurred during pregnancy or around birth and affected motor and vision functions. The study is for babies at 3-6 months up to 12 months of age and is called VISIBLE. It includes a home-based therapeutic program supported by therapists that actively engages parents in helping their babies develop. This will include parent training and fortnightly home visits. The study is about testing whether VISIBLE makes a difference in the functional abilities of infants diagnosed at risk of having cerebral palsy and vision impairment. It is also about finding out what you think of VISIBLE. Your active participation in refining VISIBLE is highly valued.

   Your baby may be eligible if they are:
   - Between 3-6 months old
   - Living in Sydney, Brisbane, Melbourne or Perth
   - At-risk for cerebral palsy
   - Experiencing visual problems due to a brain injury

   **Likely to start recruiting early 2020**
3. Stem Cells for the Brain: Are We Letting Australians Down?

Hosted by Dr Karl Kruszelnicki

The Cerebral Palsy Alliance is pleased to announce a free Public Forum: Wednesday, 4th March 2020, 6-8pm, York Theatre, Seymour Centre

Research into the potential of stem cells for treating brain conditions is progressing at a rapid pace. The aim of this Public Forum is to increase public awareness of stem cell research and therapies for brain conditions by providing information on stem cells basics, research and current knowledge/breakthroughs in this area. This event will not only be educational, but entertaining and spark important conversation. You will hear from leading experts in the field as well as consumers and ethicists. This will be followed by a panel discussion and interactive audience Q&A led by Dr Karl.

Please book your free tickets here

For any enquiries related to this event, please contact Dr Madison Paton: Madison.paton@cerebralpalsy.org.au

Please contact the Seymour Centre for booking enquiries: 02 9351 7940
IV. Community and Researchers together

Join us!

Be involved, share your lived experience and help improve cerebral palsy research.

To learn more about CP Quest, how you can join, what is involved and how you can contribute please go to our web-page: https://cerebralpalsy.org.au/our-research/get-involved-research/cp-quest/

GRIPP2 Reporting checklists

Tools to improve reporting of patient and public involvement in research.

When researchers finish their studies, the main way of telling the world about their results is by writing a report and it then being published in a medical journal. Health professionals and researchers then get access to these medical journals through their work and universities. Previously there were no guidelines about how researchers should report their findings when patients/the public are involved in health research. As a result there was often inconsistency in how researchers reported public involvement in their projects.

To address this issue, a team of researchers from the UK published the first international guidelines for reporting patient/public involvement in health research, called “GRIPP2”. The aim of the GRIPP2 checklist is to ensure good quality reporting of research projects involving public/patients when they are published in a medical journal.
The GRIPP2 checklists will help ensure that findings from the CP Quest and other consumer/researcher partnerships are reported in a consistent and transparent manner.

**CP Research Newsletter**

Want to know more about the latest cerebral palsy research?

Subscribe to a weekly update on the latest prevention and intervention research on cerebral palsy, as indexed in the NCBI PubMed (Medline) and Entrez (GenBank) databases.