Issue 3 Winter 2011

Solve! At the RCH

Apex Chair in Developmental Medicine, Professor Katrina Williams

Welcome to the third newsletter of Solve! At the RCH. Thank you to all those who have supported Solve! over the past five years. Since the launch on 8th March 2006, much has been achieved.

The Apex Chair in Developmental Medicine, Professor Katrina Williams, was selected and took up her position in January 2011. Four doctoral students are currently undertaking their studies in the department and a fifth student completed her PhD at the end of 2010. The number of publications from the department is rising steadily: 6 in 2007, 10 in 2008, 14 in 2009 and 16 in 2010. With increased funding to the department, we have been able to employ additional researchers and hence increase the research effort. Most importantly, we are disseminating our findings by presenting at national and international meetings and publishing the work in international journals.

In this newsletter some of the research projects currently being undertaken will be highlighted. But first, here are some details about the new Apex Chair in Developmental Medicine, Katrina Williams, and the Apex Foundation which has so generously contributed to the funding for this Chair.

Katrina is a paediatrician and public health physician. Katrina worked with a cerebral palsy register in London in the mid 1990s and returned to Australia in 1996. Between 1998-2005, she was a Staff Specialist in the Clinical Epidemiology Unit at Children's Hospital at Westmead and completed a PhD titled *The epidemiology and classification of autism spectrum disorders in New South Wales*. From 2005 she worked as a Community Paediatrician at Sydney Children's Hospital and Associate Professor for the University of NSW, and from 2006 she was the Co-ordinator of Clinical Research at Sydney Children's Hospital.

Katrina is involved in research about autism, child development and child populations at high risk of adverse outcomes. She also undertakes methodological research about prognosis and evidence-based medicine. Current autism research includes treatment trials, prognosis, diagnostic test accuracy studies and systematic reviews. The purpose of a systematic review is to sum up the best available research regarding a specific research question. This is done by bringing together the results of all the studies that have been published on a topic that used the most appropriate methods to answer the specific question.

A systematic review differs from other types of reviews by using procedures that are put in place prior to commencement to find, evaluate and synthesise the results of relevant research. These processes ensure that the procedures are transparent, to reduce the risk of a biased review, and can be replicated. As part of a systematic review the similarities and differences of studies included in a review, with regard to methodological quality and clinical characteristics, are described.

Katrina is a member of the Steering Group of the Cochrane Collaboration, the Australian Representative to the Advisory Board of the Cochrane Collaboration Child Health Field and co-convenor of the newly formed Cochrane Prognosis Methods Group. She is an editor for Cochrane Developmental, Psychosocial and Learning Difficulties Review Group, Child: Care, Health and Development and Evidence-Based Child Health: A Cochrane Review Journal.

There is an opportunity to hear Katrina speak. She will present the Dean's Lecture on 21st June at 6 pm. The title of her talk is *Autism: so many questions and so few answers*. Please RSVP to 8344 9800 or mdhs-rsvp@unimelb.edu.au

The venue is:
Law Theatre GM15, Level 1
Law Building (106)
University Square, 185 Pelham Street
The University of Melbourne, Parkville
(Melways reference: Map 2B C9)

Apex Foundation for Research into Intellectual Disability

The Apex Foundation for Research into Intellectual Disability (AFRID) was the culmination of years of outstanding community service activities undertaken by Apex clubs in Australia. In the 1960s, Apex clubs provided facilities, equipment and support for people, especially children, with an intellectual disability. In 1967, the Association of Apex Clubs of Australia established AFRID as a lasting effort to continue their work and support.

During the initial three years of community activities, Apex clubs generated and donated over $100,000 to intellectual disability support and research. In the three decades since, AFRID has donated more than $1.0m toward a variety of research projects identified as making a meaningful contribution to unlocking the mysteries of intellectual disabilities. In recent times, the Foundation has been in a position to provide up to $80,000 in research grants each year.

In 2007 AFRID and Solve! At the RCH undertook discussions regarding funding the Chair in Developmental Medicine. During the August 2007 Board meeting, AFRID moved to formally pledge $1.25m to this project. The association between AFRID, the Department of Developmental Medicine at RCH, Solve! At the RCH and the Faculty of Medicine, Dentistry and Health Sciences at the University of Melbourne will be a powerful force in the field of Developmental Medicine.

What is Solve! At the RCH?

New readers may not be aware of what Solve! At the RCH is all about. Here is some background information.

Disability in childhood

Disability poses a significant problem for children, their parents, extended families and for society. It is a lifelong problem with a continuing need for support and special assistance. There are almost 300,000 children aged 0 – 14 years in Australia with a significant disability. Despite these large numbers and significant impact, the causes of many disabilities remain unknown and the best treatment methods often uncertain.

The Department of Developmental Medicine at The Royal Children's Hospital

Developmental Medicine cares for children with disabilities, particularly children with cerebral palsy, spina bifida, autism spectrum disorders, intellectual disability and multiple disabilities.

There are about 3000 outpatients per year, an inpatient service and an extensive teaching program. The Uncle Bobs Child Development Centre is also part of the department.

Over the past 25 years, the department has established a research program with two aims: firstly to increase knowledge about the causes of disability with the hope of developing preventive strategies, and secondly to evaluate treatment methods to ensure that the optimal interventions are provided for children and their families.

As a result of this work there have been significant improvements in the way children with disabilities are treated. Additionally, there have been numerous conference presentations and over 100 publications in refereed journals.

Solve! At the RCH

In 2004, staff from Developmental Medicine decided that it was time to take the research program to the next level and create a Centre of Developmental Disability Research. A competition was held for the children that attend our department, to find a suitable name. Ariane Garnerwilliams and Jonty O'Callaghan independently suggested 'Solve' which was subsequently adopted.

Mission

The Mission of Solve! At the RCH is to improve outcomes for children with disabilities and to better understand and prevent the causes of disability. A strategic plan was developed. The major aims were to secure funding to:

- increase the research output in childhood disability with the objective of preventing some cases, and improving outcomes for children with established disabilities;
- encourage more postgraduate students from disciplines including medicine, psychology, physiotherapy, occupational therapy and speech pathology to undertake research in this field;
- become one of Australia's leading clinically based research centres specialising in developmental disability.

A further aim was to create a Chair of Paediatric Developmental Medicine, to lead the research effort and to ensure sustainability into the future. We are excited that this aim has been achieved.

Update on the Victorian Cerebral Palsy Register

The Victorian Cerebral Palsy Register collects information about people with cerebral palsy born or residing in Victoria since 1970. It has several important aims.

1. **It enables study of the occurrence and characteristics of people with cerebral palsy in Victoria. There is also an Australian Cerebral Palsy Register to which the Victorian Register contributes data.**
2. **It is an important planning tool providing crucial data for medical, disability and education services.**
3. **It is a wonderful resource for research studies. The Victorian Cerebral Palsy Register draws from a greater population base and has been in existence for a longer period of time than most other Registers, placing it in a unique position to contribute knowledge to the field.**

There are currently 4666 individuals on the Victorian Cerebral Palsy Register and the outcomes achieved include:

- 41 publications in refereed journals with the numbers steadily increasing with four prior to 2000, 26 between 2000 and 2009, and 11 since the start of 2010.
- 26 completed and 21 current projects, most involving collaborative groups from different hospital departments, community organisations and universities
- 49 presentations at national/international meetings including papers at the Royal Australasian College of Physicians meetings in 2009, 2010 and 2011; six papers at the American Academy of Cerebral Palsy and Developmental Medicine over the past two years; and two papers at the Australasian Academy of Cerebral Palsy and Developmental Medicine in 2010
- Five PhD students have used the Register for their projects.
- The Register has gained in profile and is used to provide information to parents and professionals.

Three highlights of recent research from the Register

Cerebral palsy and assisted reproductive technologies

The aim of this project was to determine whether assisted reproductive technologies (ART) were more likely to be the method of conception in children with cerebral palsy than in those without cerebral palsy. Children with cerebral palsy (single births) born between 1991 and 2004 were selected from the Register and matched for birth year to two children randomly selected from the Victorian Perinatal Data Collection Unit ('controls'). Data from both sources were linked to records from three ART centres. We identified 1241 children with cerebral palsy and 2482 controls. There was no significant increase in the odds of children with cerebral palsy being conceived using ART, reassuring information for both parents and health professionals.

(Reid SM, Jaques AM, Susanto C, Breheny S, Reddihough DS, Halliday J. Cerebral palsy and assisted reproductive technologies: a case-control study. Dev Med Child Neurol. 2010; 52 (7): e161-e66.)

Children with cerebral palsy and normal brain MRI scans

Between 9% to 16% of children with cerebral palsy have normal brain magnetic resonance imaging (MRI) scans. Testing for metabolic and genetic conditions for these children has been recommended. This study identified a group 54 children born between 1999 and 2005 with normal imaging, described their clinical features and assessed the value of testing for metabolic disorders. Children without spasticity and those with milder clinical severity were more likely to have normal imaging. Twenty-three children were assessed clinically and further investigated. No new diagnoses were made. We concluded that although it is important to consider metabolic causes in individual children, the chances of finding a metabolic problem are small.

(Leonard JM, Cozens AL, Reid SM Fahey MC, Ditchfield MR, Reddihough DS. Should children with cerebral palsy and normal imaging undergo testing for inherited metabolic disorders? Dev Med Child Neurol 2011, 53: 226–232.)

Rates of cerebral palsy in Victoria and in other parts of the world, between 1970 and 2004

The aim of this study was to assess overall and gestational age-specific trends in the rate of cerebral palsy in Victoria, and to compare these findings with other population data. Individuals born in Victoria, 1970-2004, were identified from the Victorian Cerebral Palsy Register; 3491 were included in the study. Comparison data were extracted from nine registers in different parts of the world including one other Australian register (Western Australia). There was an increase in the rates of cerebral palsy over the 1970s and 1980s, consistently seen in extremely preterm (<28 weeks) survivors but also in those born at term (37+ weeks). This may have been partly due to the increasing survival of extremely preterm infants which occurred without a concomitant improvement in neurological outcomes. Fortunately, since the early 1990s, cerebral palsy rates either stabilised or decreased, particularly for children born extremely preterm. However, it is disappointing to find no actual decrease in overall cerebral palsy rates.

(Reid SM, Carlin JB, Reddihough DS Rates of cerebral palsy in Victoria, 1970-2004: has there been a change? Accepted for publication in Developmental Medicine and Child Neurology April 2011).

Learning if brain scans help to predict how children with cerebral palsy perform everyday activities

A new study has begun to deepen our understanding about children who have an injury to the 'white matter' of their brain.

This type of injury was thought to occur mainly in children born prematurely, however now it is known to also happen in children born near or at term. We hope to find out if children with white matter injury who are born prematurely have more difficulties with functional activities (such as walking, playing with toys, dressing themselves and communicating with family and friends) than children with the same injury who are born at term.

A senior physiotherapist and occupational therapist are inviting families of children aged 4 to 11 years who have a white matter injury to participate. Children and families who agree to be involved meet with the therapists on one occasion and will have a discussion about their child's ability to perform various activities. The information about each child's level of function will be compared with the brain scan the child had earlier in life.

This information will help inform new parents of children born with cerebral palsy about what they might expect their child to be able to do as they develop. It may also assist in optimizing the provision of therapy services. Whilst work has started on this study, further funding is needed for detailed measuring of each child's brain scan. We hope that as many children as possible with white matter injury will take part. If you have any questions or you would like to participate, please contact either Adrienne Harvey or Melinda Randall on 9345 4529.

What needs to be done now?

The help of all our supporters is much valued and has enabled us to make a start in the important task of learning more about the causes and outcomes of disabilities in childhood. More still needs to be done. Funds are required to undertake this essential work which has the long term goal of improving outcomes for children and their families. Disability research is poorly supported today and to achieve ours aims we need funding for:

- Small research projects, at a cost of $10,000 – $50,000
- Research assistants, at a cost of $56,000 to $77,000 per annum;
- Research Fellowships in Developmental Medicine, at $100,000 per annum;

Every dollar raised will make a difference to the work that we do for children with disabilities and their families.

No contribution is too small. You can be sure that for every dollar that Solve receives:

- Someone's hope will be restored
- We will be closer to preventing disability
- Ensuring the best outcomes for children with disabilities everywhere.

YES, I would like to help children with disabilities and their families by supporting SOLVE! At the RCH

I would like to donate $ by

❑ Cheque (payable to The Royal Children's Hospital Foundation) ❑ Money order ❑ Credit card

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