SOLVE@RCH ANNUAL REPORT

JULY 2012 - DECEMBER 2013

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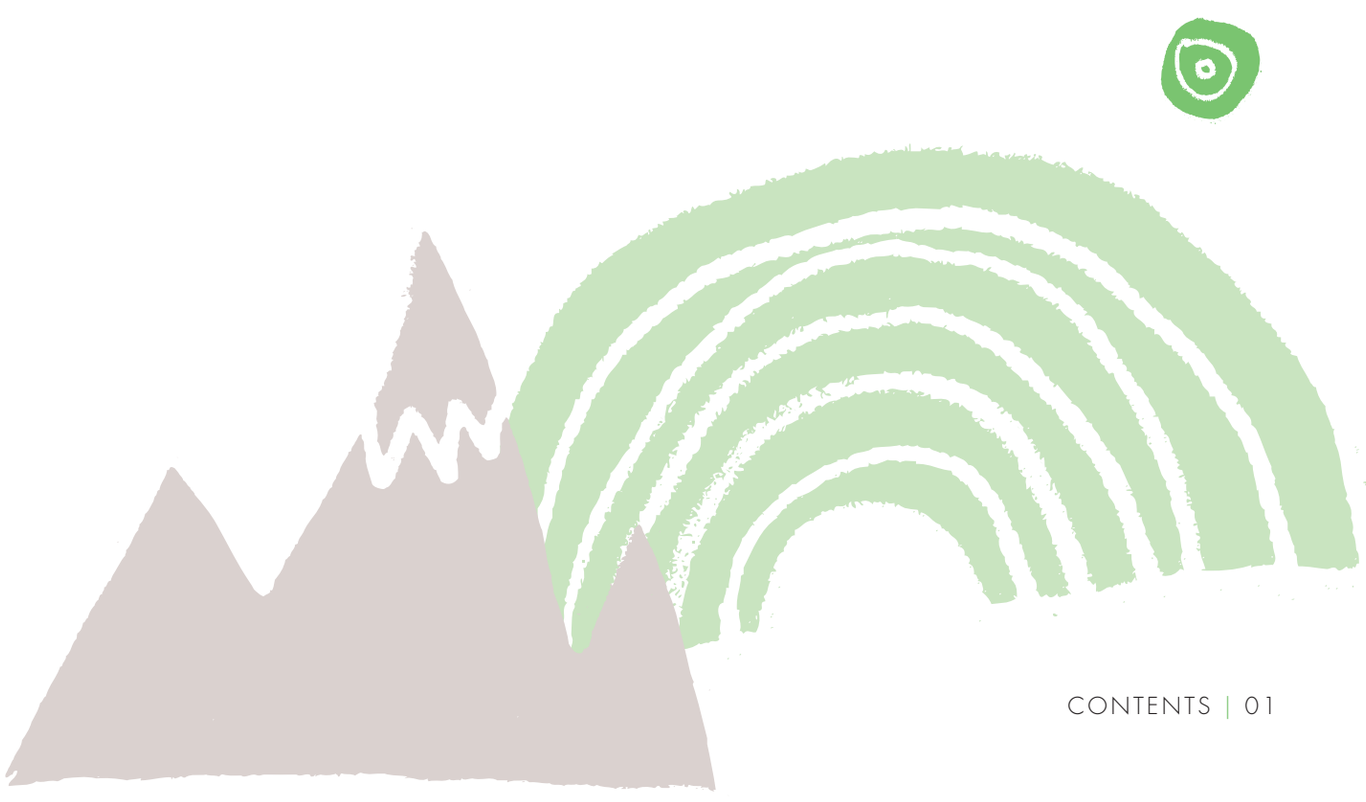


CHAIR OF THE ADVISORY PANEL

The past 18 months represent a watershed in the development and growth of Solve@RCH and so it is with great pleasure that I am introducing this Report.

Thanks to the extraordinary generosity of the Lorenzo and Pamela Galli Foundation a new Chair in Development Medicine has been endowed.

The earnings from this endowment will be sufficient to create and fund a new professorial position which will complement the ground-breaking work being undertaken by Professors Katrina Williams and Dinah Reddihough in autism and cerebral palsy, respectively.

Professor Dinah Reddihough has been successful in securing an NHMRC grant for $2.5 million over 5 years to establish Australia's first Centre for Research Excellence in Cerebral Palsy.

The partnership with the Apex Foundation for Research into Intellectual Disability continues to flourish. Stronger and deeper relationships have also been built with the University of Melbourne, the RCH Foundation and Murdoch Childrens Research Institute.

The focus on research and encouraging some of Australia's best and brightest medical and allied health professionals to train at Solve@RCH is also bearing fruit with record levels of publications in refereed journals, conference invitations, PhD and other degree students.

The Victorian Cerebral Palsy Register continues to gain more national and international recognition as the best cerebral palsy database in the world and we are grateful to the Victorian Medical Insurance Agency, and the Victorian Department of Human Services for their contributions to maintaining and building this vital research platform.

The commencement of the National Disability Insurance Scheme has drawn public attention to the reality of disability in Australia, and Solve@RCH will become a vital part of its research base.

Bruce Bonyhady AM
Chair of the Advisory Panel

EXECUTIVE SUMMARY

There have been major achievements over the last eighteen months which speak to the success of bringing together a highly motivated research and training team, expert clinicians and a passionate and active advisory panel that includes experts, consumers and fundraisers. Professor Dinah Reddihough, working in collaboration with Australian and international expert colleagues, was awarded a Centre of Research Excellence Grant for cerebral palsy by the National Health and Medical and Research Council (NHMRC). This prestigious grant speaks to the teams established track record of excellent collaboration, research productivity, effective implementation of evidence to service delivery and training expertise. This funding will provide the opportunity to develop new evidence about treatments for cerebral palsy and to ensure evidence translation through training, guideline development, service and policy. Solve@RCH in partnership with the University of Melbourne has also attracted funding for the Lorenzo and Pamela Galli Chair of Developmental Medicine, and recruitment for that appointment is currently underway.

Our publications have helped attract funding from competitive research grants, and we continue to be supported by government and philanthropic funders. We applaud the success of Dr Sue Reid, who secured both an NHMRC Career Development Award and a New Investigator Grant. The final decisions for other grant applications are still awaited, with submitted applications including projects exploring epigenetic causation of autism and developing ways to assess quality of life of children with intellectual disability.

I'd like to thank all staff and panel members and acknowledge our colleagues Kevin Collins and Janet Walstab, who have retired. I'd also like to thank Chloe Shorten, who has recently stepped down from the advisory panel, for her input and ongoing support.

The Victorian Cerebral Palsy Register (VCPR) continues to be an essential platform that enables ground-breaking research and remains a 'go to' source for Victorian, national and international work. New partnerships and technological opportunities are shaping the VCPR to have an even greater impact over time. Our training sessions for parents and professionals have expanded in both quantity and reach through our training coordinator.

Our work is based on the needs of children with developmental disabilities and their families. We are trying to answer really big questions about the causes of neurodevelopmental disability, and at the same time, improve the lives of children with disabilities today by ensuring that we provide the best current care and a better future. We are working towards a future in which we will make accurate diagnoses of neurodevelopmental disability that will link directly to individually tailored effective and low-risk interventions that maximise function and participation. Opportunities for extending our partnerships and collaborations will allow construction to speed up on this important endeavour.

Prof. Katrina Williams
APEX Australia Chair of Developmental Medicine, University of Melbourne
Director, Developmental Medicine, Royal Children's Hospital

KEY PARTNERS & FUNDERS

Melbourne Children's

Excellence in clinical care, research and education

The Royal Children's Hospital Melbourne

Murdoch Childrens Research Institute

The University of Melbourne

A·F·R·I·D APEX FOUNDATION FOR RESEARCH INTO INTELLECTUAL DISABILITY LTD

APEX Foundation for Research into Intellectual Disability

PSA Professional Services Australia

Victorian Medical Insurance Agency

The Royal Children's Hospital Foundation

Royal Children's Hospital Foundation

Australian Government Department of Health

Department of Health

WILLIAM COLLIE TRUST

THE LORENZO AND PAMELA GALLI CHARITABLE TRUST

OUR VISION

VISION

To provide leadership in children's disability research, best practice, advocacy and public policy

MISSION

To improve the health and wellbeing of children with disabilities and their families and better understand the causes of developmental disability

GOALS

To be a transdisciplinary and intersectoral centre of research excellence that will:

- advance understanding of the causes of developmental disability
- develop and test prevention and treatment strategies
- improve the way we provide care and services for children with disability and their families

OBJECTIVES

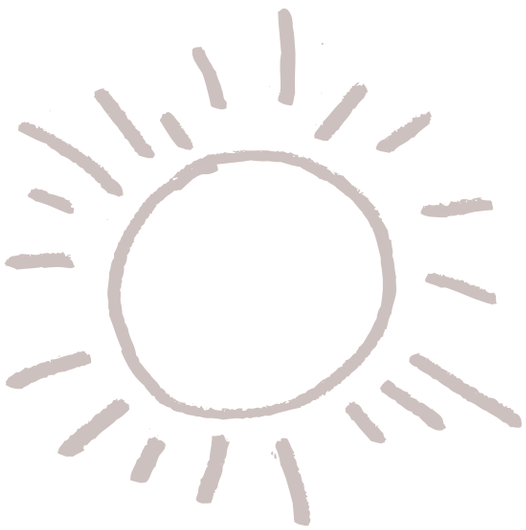
- Build developmental disability data resources
- Work collaboratively with other organisations involved in the care of children with disabilities and relevant research organisations
- Increase the future workforce of developmental disability clinician researchers and scientists
- Raise the profile of research in developmental disabilities

KEY RESEARCH ACTIVITIES

- Building crucial research infrastructure
- Undertaking discovery research
- Embedding best evidence in clinical care, service and policy

UNDERPINNING PRINCIPLES

- Transdisciplinary research is needed to make advances in research
- True collaboration is needed to achieve our mission
- All potential conflicts of interest in research should be transparent
- That attracting funding and publishing our findings are necessary activities on the pathway to achieving our objectives but are not the desired end point
- Shared knowledge and experience will hasten achievement of our mission
- Information will be disseminated to all who need it



OUR HISTORY

In 2004 the Centre of Developmental Disability Research was formed because of the urgent need to increase knowledge about both the causes of disability in childhood and the outcomes of treatment. The Centre was renamed *Solve@RCH* and launched by Sir Gus Nossal on 8 March, 2006.

Since then there has been an exponential increase in research activities, resulting in significant improvements in the way we treat children with disabilities, that have been associated with cost savings for the community, as well as emotional and financial benefits for families. Many new research collaborations and partnerships have been established adding skills as well as financial resources to the efforts of the team. In particular, the relationships built with the Cerebral Palsy Alliance (New South Wales), Latrobe University and Monash University (Victoria) and CanChild (McMaster University, Canada) have been helpful. The research program developed has also created an investment in the future by providing opportunities at undergraduate and graduate levels for students to undertake research that will deepen their understanding of disability. This has led to growth in the numbers of highly qualified and experienced professionals in the field of developmental disability, leading to superior health practice and service delivery improvements.

In 2011 the first Chair in Developmental Medicine in Australia, the APEX Australia Chair of Developmental Medicine, was created in partnership with the Apex Foundation for Research into Intellectual Disability, the University of Melbourne and the Royal Children's Hospital Foundation. Professor Katrina Williams, a leader in autism research, was appointed as both the Chair and as Director of the Department of Developmental Medicine at the Royal Children's Hospital.

Professor Dinah Reddihough AO, stepped down as Director, Developmental Medicine in 2011, after engineering the growth of the department and its many achievements and being instrumental in the development of the Chair in Developmental Medicine. Dinah was awarded a University of Melbourne Vice Chancellor's Fellowship in 2011 and is continuing her great work in both the research program and development of best practice clinical services within Solve@RCH.

In 2013, the Lorenzo and Pamela Galli Foundation generously donated a gift of $5 million to establish the Lorenzo and Pamela Galli Chair in Developmental Medicine. This new position will attract a world leader in neurodevelopmental research, to further expand, diversify and deepen the research output of Solve@RCH.

SOLVE@RCH

Solve@RCH is a research and evidence-translation endeavour focused on the breadth of developmental problems and disability in children. Solve@RCH is a clinically embedded child development and disability research centre, well-placed to conduct excellent clinical and discovery research, and translate evidence to practice and service delivery.

Solve@RCH is a partnership between the Department of Developmental Medicine at the Royal Children's Hospital, the University of Melbourne and Murdoch Childrens Research Institute. Employees of all three institutions - working as clinician researchers, scientists and administrators - have links to non-government services and other public sector services at both federal and state levels in health, education and community services.

All our research aims to minimise impairments and activity limitations, and promote participation and wellbeing of children with developmental disability and their families.

Solve@RCH is governed by the Royal Children's Hospital professional and ethical standards and its own Advisory Panel. It is located at the Royal Children's Hospital and is embedded in the three campus partners of Melbourne Children's: the University of Melbourne, the Royal Children's Hospital, and the Murdoch Childrens Research Institute.

This report highlights achievements over the last 18 months and presents key current activities, within the context of the current landscape for research, service delivery and policy for children with developmental disabilities and their families.

DEVELOPMENTAL DISABILITY

Eleven percent of males and six percent of females aged 5-14 years have a disability. There are many different types of developmental disability (Figure 1) with problems predominantly affecting motor ability (like cerebral palsy and spina bifida), communication and social interaction (like autism spectrum disorders) and intellectual function (intellectual disability) or vision and hearing. Some developmental disabilities have known genetic causes (like Down Syndrome and Prader-Willi Syndrome) while for others the cause is multifactorial and only known in a minority of cases (cerebral palsy, autism spectrum disorder and intellectual disability).

For most children with a developmental disability there are increased lifelong needs for health care, specialised education, employment and other community support. These needs bring increased financial, physical and emotional costs for families. Meanwhile there has been little progress in preventing developmental disability. The second figure shows that the prevalence of cerebral palsy is remaining relatively constant. The prevalence of autism spectrum disorders in Australia has increased from 1 in 160 in 2005 to over 1 in 100 today.

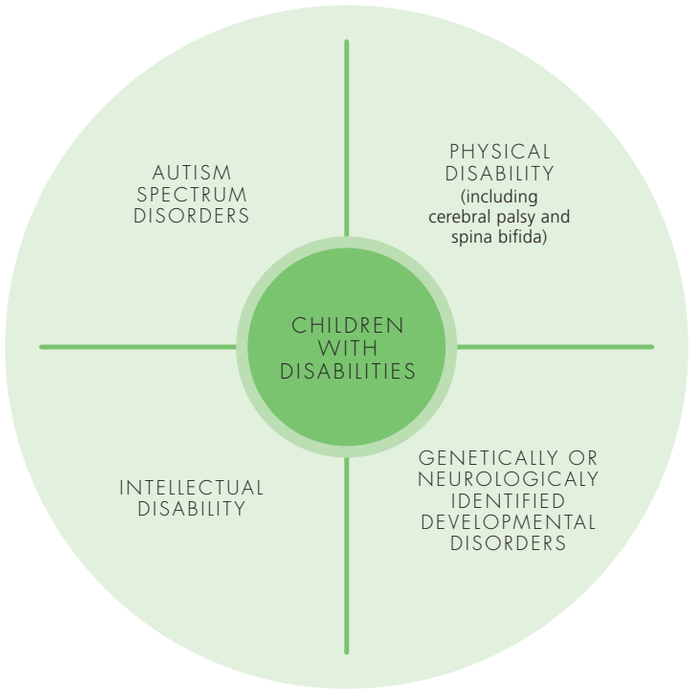


FIG.1. DIFFERENT TYPES OF DEVELOPMENTAL DISABILITY

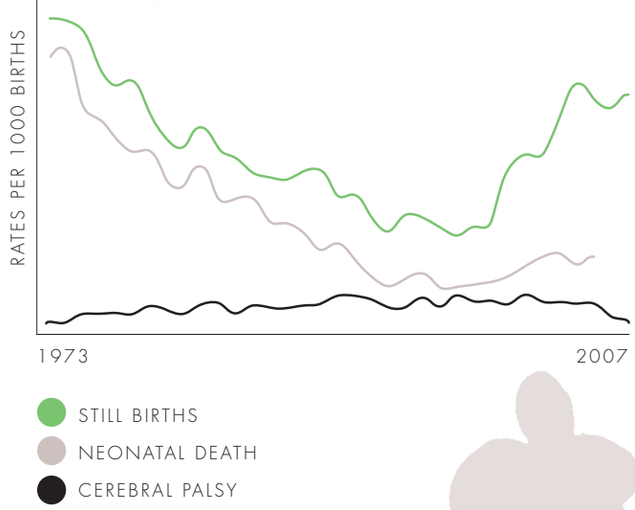
We need to build on what we know and learn more about the best ways to minimise impairments and activity limitations and maximise participation of all those affected by developmental disability. We also know less than we should about the life course of those affected and their changing needs over time.

There are no established mechanisms for monitoring the interventions that are provided for children and their families nor the outcomes of existing and new funding models.

In July 2013, the Australian Government implemented a trial of the National Disability Insurance Scheme (NDIS) in Tasmania, South Australia and certain parts of New South Wales and Victoria.

NDIS is a major development for both children with disabilities and their families, and service providers, providing individualised support for those in need. Research undertaken at Solve@RCH will inform the best-practice implementation of this scheme and help benefit children with disabilities and their families all over Australia.

FIG.2. CEREBRAL PALSY, NEONATAL DEATH AND STILLBIRTH RATES IN VICTORIA 1973 - 2007



PROFILES: OUR DIRECTOR

KATRINA WILLIAMS

Professor Katrina Williams is the Director of Solve@RCH and the Apex Australia Chair of Developmental Medicine at the University of Melbourne. She has worked as a clinician and researcher in the area of developmental medicine since 1996.

"Developmental medicine is concerned with problems of neurodevelopment, which can present early in life or in early childhood or at school age years. It encompasses conditions that are described currently as cerebral palsy, autism, intellectual deficit disorders, and also some disorders that have known genetic causes, but have a complex and chronic component of neurodevelopmental disability," she said.

Professor Williams' primary area of research is autism, with recent and ongoing studies focusing on assessing outcome measures, trials of potential treatment, comparisons of educational approaches to improve outcomes of affected children, trials of different early intervention approaches and studies into the disorder's prognosis. This work has made her a well-known and highly respected figure in the developmental medicine area, and a perfect choice to head a world-class research organisation like Solve@RCH.

Her expertise in autism also complements the expertise of her research colleagues, such as Professor Dinah Reddihough, who has worked for over three decades in the area of cerebral palsy. This allows Solve@RCH as a whole to focus on many research areas simultaneously and improve the lives of as many children with developmental disabilities as possible.

Under Katrina's direction, Solve@RCH continues to thrive. In 2013, the Lorenzo and Pamela Galli Charitable Trust generously established a new Chair of Developmental Medicine, which will attract a world leader in neurodevelopmental research and a wider team of researchers, further increasing the already impressive research output of Solve@RCH.

"Today we're at the forefront of discovery in brain development. There's a lot going on worldwide to think about how the brain works and the sorts of things that cause problems with brain function. It's really important to put a spotlight on early brain development, and the new Chair brings us the opportunity to do just that," she said.

While the Royal Children's Hospital possesses state-of-the-art equipment, the technological landscape in medical research and clinical care is constantly shifting. The Lorenzo and Pamela Galli Chair of Developmental Medicine and its associated funding will also grant Solve@RCH greater access to new technologies. Katrina is excited about how they will bolster the research output of the organisation.

"In the last five to ten years, there's been enormous advancement in technologies that are going to help us move developmental disability and our understanding of it to the next level. MRI technology, including functional MRI technology and all the genetic breakthroughs, are really going to help us tease out the causes of developmental disabilities that we see," she said.

Improving the lives of families is Professor Williams' greatest motivation.

"We want everything we do to be relevant to children with developmental disabilities and their families," she said.

"Our research at Solve@RCH is done in partnership with the families we work with: we want the outcome of our research, now and in the future, to be directly applied to improving the identification, diagnosis, treatment and outcomes of children with developmental disabilities."

OUR CHAIR

BRUCE BONYHADY

Bruce Bonyhady has a bold vision for Australia – one where children with disabilities and their families will receive world-class care and support regardless of their social circumstances – and he won't stop until that vision is reached.

Bruce is not only the Chairman of the Solve@RCH Advisory Panel but also the President of Philanthropy Australia, and was previously the Chairman of Yooralla. His deep commitment to disability care and research stems from his family: two of Bruce's sons, Michael and Greg, were born with cerebral palsy.

Michael's diagnosis was delayed by a paediatrician who was scared of telling Bruce and his wife the truth. It wasn't until they sought out Professor Dinah Reddihough at the Department of Developmental Medicine at the RCH that they were given the information they needed.

"I'm still angry about that misinformation, because Mike's developmental delay should have been so clear. We reassured ourselves that everything was alright, but it became clear it wasn't. That's when we went looking for a doctor that could really help us: that's when we found Dinah," he said.

His family's experiences at the RCH led to the start of Bruce's long working relationship with Professor Dinah Reddihough and his involvement with the beginnings of Solve@RCH.

"The support we received then and have received since is why my wife and I are so committed to what the Department of Developmental Medicine is doing and what Solve@RCH is doing," he said. "Dinah's been the most important advisor to us as a family over nearly thirty years."

Michael and Greg received world-class care and support at the RCH, but Bruce recognises that many children and families are not as fortunate.

"Today, services for people with disabilities are really a lottery – it depends on where live or how the disability occurred, or the name of the disability, or when it happened. The system is deeply unfair and it offends my sense of what's fair and just," he said.

This sense of justice drove him to develop a plan for a nationwide policy for disability care, which would later become the National Disability Insurance Scheme – a name coined by Bruce and his colleagues in a submission to the 2008 20/20 Summit. The inspiration for such a scheme was born during a conversation between Bruce and former Deputy Prime Minister Brian Howe about the nature of comprehensive disability care.

"It was one of those light bulb moments where it was clear – the whole population is at risk, but you can't buy the insurance on the private market. We're all at risk and we should all contribute to it, just in the same way as we all contribute to health insurance through the Medicare levy," he said.

There's no doubt Bruce's professional background in funds management and insurance prepared him for the monumental task of developing the NDIS, which is currently being rolled out in South Australia, Tasmania and select parts of Victoria and New South Wales. He is the inaugural Chairman of the Board of the National Disability Insurance Agency, which oversees the scheme, and will be directly involved with the implementation of the program he helped initiate.

He sees the approaches of Solve@RCH and the NDIS as complementary: the former nurtures cutting-edge research into the treatment and potential prevention of disability, while the latter exists to support all Australians who do, and will, have a disability in the future. By being an integral part of these important arms of disability care in Australia, Bruce is contributing enormously to the area.

"It's essential that research informs the NDIS, so that it becomes best-practice and there is an evidence base on which that practice can be developed. The leverage from the sort of research that Solve@RCH is doing will be enormous," he said.

In 2010, Bruce was appointed a Member of the Order of Australia for his service to people with disabilities, their families and carers, and to the community – well-deserved recognition for a life of contribution to important organisations. But he feels his work is far from over.

"Disability and living with disability has been a really important part of our lives as a family and in many ways I think we've been incredibly fortunate, because we've had both the financial resources and the family supports and family resilience to deal with the life challenge in this area," he said.

"But so many do not, and that's why I'm so committed to helping Solve@RCH to grow and develop."

OUR FAMILIES

JONTY AND KATIE O'CALLAGHAN

The lives of Jonty O'Callaghan and his mother Katie are intricately entwined with Solve@RCH. Born prematurely, Jonty was diagnosed with cerebral palsy at the Royal Children's Hospital at the age of only six months. But the knowledge and expertise of the developmental medicine professionals at the RCH now allows him to live a fulfilling and active life alongside his three siblings.

"Ever since I can remember the staff at the RCH have always been very supportive of my development and my growth, enabling me to get the most out of myself and minimise the damage that my premature birth had," Jonty said, now 16 years old and a student at Xavier College.

For 10 hours a week over 15 years, Jonty has undergone physiotherapy, occupational therapy and speech therapy at the RCH. Katie's training as an occupational therapist has made her realise how much methods have changed for the better in that time, and why rehabilitation needs to continue to improve.

"Therapy has been through lots of phases of evolution," she said. "A lot of time is spent in rehab and because it's a little child and that's their playtime, it's important for each hour of therapy to be effective and the techniques to be cutting edge."

Katie and Jonty's positive experiences at the hospital set the scene for Katie's involvement in the creation of Solve@RCH and her subsequent Advisory Panel long-term role in the organisation. She currently sits on the Solve@RCH panel.

"My initial representation was as a parent of Jonty, but over the years, it's evolved. I feel it's less and less directly connected with Jonty and his future, and more about just having that knowledge of bringing up a child with cerebral palsy and how I can help make a contribution to the community for all future parents of children with cerebral palsy," Katie said.

But it's not just Katie who has made a lasting contribution to the organisation.

"A few years ago, my Mum gave me an idea that I might be able to come up with a name for it, so I gave a bit of thought to it and came up with 'Search and Solve'. They came back with 'We like Solve', and I thought 'Great!'" said Jonty.

His motivation to overcome his physical disability has also opened some sporting doors. He is now involved in the International Paralympic Races in downhill skiing in the winter and plays cricket in the summer - impressive achievements for a young man who, at one point in his life, couldn't freely move the right side of his body.

"I've progressively improved my skiing, going from an intermediate level to a racing standard over the last five or six years. I enjoy the exhilaration and adrenaline rush you feel from the moment you're at the start gate all the way to the finish; it's almost a journey in and of itself," he said.

The future also looks bright for Solve@RCH, with an increasing number of young medical professionals and bright medical students joining the organisation at the RCH.

"I think that what's happened in the short space of time with Solve@RCH is quite amazing. We've gone from being just a group of little projects under a banner, into an organisation that is known worldwide and actually conducting research of international standard and published and presented all around the world," Katie said. "We have a fantastic Chair of Developmental Medicine in Katrina Williams, who drives a really great agenda and brings a lot of integrity and professionalism into the department."

But for Katie and the rest of the O'Callaghan family, the most important thing is that Solve@RCH continues to support children with disabilities and their families.

"Jonty, I believe, has achieved everything that my other children have achieved, it's just been harder work for him, but he has got there. Without the support of knowledgeable professionals, that would have been much harder."

OUR STAFF

SUE REID

Sue Reid's vital research into the causes of cerebral palsy has been nurtured at Solve@RCH.

She's a key researcher of developmental disability in Victoria and a part of the Developmental Disability and Rehabilitation Research group at the Murdoch Childrens Research Institute (MCRI). She is also Manager of the Victorian Cerebral Palsy Register (VCPR).

She completed her PhD in the epidemiology of cerebral palsy in 2012, in conjunction with the MCRI.

Her research at the MCRI focuses on the classification and assessment of brain scans of children with cerebral palsy, collected using the VCPR, to try and find relationships between the scans and the types of cerebral palsy diagnosed.

"I am currently planning in-depth studies of the characteristics of brain scans within each classification of cerebral palsy, which may lead to descriptions of causal pathways to cerebral palsy," she said.

This research will have crucial implications for the way the suite of conditions is diagnosed and treated in children from Australia and around the world.

Her work managing the VCPR has led to increased knowledge about symptoms of cerebral palsy, including drooling and spasticity, through collaborative work with other researchers at Solve@RCH and the Murdoch Childrens Research Institute.

While Sue's research had already been highly collaborative across multiple institutions, the appointment of the 2011 Apex Chair of Developmental Medicine has and continues to improve her opportunities and help her generate world-class results.

"The Chair has been vitally important in raising the profile of developmental disability within the Melbourne Children's campus and within the medical profession as a whole. It has enabled us, as a group, to increase the breadth of our research in developmental disability," she said.

"It has also facilitated collaborations between clinicians and researchers that will assist us in building a strong evidence base for how we manage children with disability."

As a former physiotherapist, Sue understands the importance of the link between clinical practice and research. In 2001, she started to work in developmental medicine at MCRI, leading into a Masters' degree in Clinical Epidemiology and a career in research.

Early in life, Sue was motivated to start working with children with developmental disabilities by volunteering at holiday camps for children and their families.

"I not only saw first-hand some of the difficulties they face, but also grew to appreciate them for who they are, and for their warmth and sense of humour," she said.

Sue recently received an Early Career Fellowship and a Project grant from the National Health and Medical Research Council – prestigious achievements for a researcher undertaking her first postdoctoral position – and is now a core part of the research team at Solve@RCH.

"Solve@RCH has been instrumental in providing the resources to facilitate research into cerebral palsy. They have supported me throughout my doctoral studies and continue to do so as I embark on my postdoctoral work," she said.

"I highly recommend their supportive environment to other students and researchers who are keen to undertake research in developmental medicine."

Her ultimate goal is to identify possible strategies for preventing future cases of cerebral palsy, a goal shared with many of the researchers at Solve@RCH, as well as families with a history of the condition.

RESEARCH ACHIEVEMENTS

HIGHLIGHTED PROJECT IN BRIEF 2012-2013

REID, S. M., MCCUTCHEON, J., REDDIHOUGH, D. S. & JOHNSON, H. 2012c. Prevalence and predictors of drooling in 7 to 14 year old children with cerebral palsy: a population study. *Developmental Medicine and Child Neurology*, 54, 1032-1036.

A self-report questionnaire was used to collect data on drooling from parents of children aged 7-14 years registered with the Victorian Cerebral Palsy Register. A total of 385 children were studied. After adjustment for factors related to severity, 40% of children were reported to have experienced drooling between four years of age and the time of completing the questionnaire. A significantly higher prevalence of drooling was found in children with poor gross motor function and in those with more severe presentations of cerebral palsy, including poor head control, difficulty with eating, and inability to sustain lip closure. Drooling was shown to be significantly associated with both intellectual disability and epilepsy. With a prevalence of 40%, drooling is an important co-morbidity in cerebral palsy and may have a substantial impact on children and families. Poor oromotor function was associated with drooling and could be the target of interventions for this under-researched problem.

DAVIS, E., MACKINNON, A., DAVERN, M., BOYD, R., BOHANNA, I., WATERS, E., GRAHAM, H. K., REID, S. & REDDIHOUGH, D. 2013. Description and psychometric properties of the CP QOL-Teen: a quality of life questionnaire for adolescents with cerebral palsy. *Research in Developmental Disabilities*, 34, 344-352.

The Cerebral Palsy Quality of Life Questionnaire (CP QOL) for Adolescents called CP QOL -Teen measures wellbeing and participation; communication and physical health; school wellbeing; social wellbeing; access to services; family health; and feelings about functioning. The psychometric properties of the CP QOL-Teen were measured using Cronbach's alphas for the derived scales ranged from 0.81 to 0.96 (primary caregiver report) and 0.78 to 0.95 (adolescent report). Test–retest reliability (4 weeks) ranged from 0.57 to 0.88 for adolescent self-report and 0.29 to 0.83 for primary caregiver report. Moderate correlations were observed with other generic and condition specific measures of QOL, indicating adequate construct validity. Moderate correlations were observed between adolescent self-report and primary caregiver proxy report. This study demonstrates acceptable psychometric properties of both the adolescent self-report and the primary caregiver proxy report versions of the CP QOL-Teen

GREENWOOD, V., CRAWFORD, N., WALSTAB, J. & REDDIHOUGH, D. S. 2013. Immunisation coverage in children with cerebral palsy compared to the general population. *Journal of Paediatrics and Child Health*, 49, E137-E141.

This is the first report of the immunisation status of an Australian cohort of children with cerebral palsy (CP). The vaccination status of children with CP aged less than 7 years (449 children from the Victorian Cerebral Palsy Register) was compared with that of the general population using the Australian Childhood Immunisation Register (ACIR). Eighty-six or 19.2% (95% confidence intervals 15.6–23.1%) of the children with CP were not 'up to date' (NUTD) with the Australian immunisation schedule at the time of the ACIR data linkage (13 March 2009) which is well above the general population percentage (range 6.4–8%). All children with CP under 15 months of age were NUTD. This study highlights that children with CP are at high risk of incomplete and delayed immunisation, a significant problem given the increased health-care needs of this patient group and their increased vulnerability to the complications of vaccine-preventable diseases.

HARVEY, A., BAKER, L. & WILLIAMS, K. 2013a. Non-surgical prevention and management of scoliosis for children with Duchenne muscular dystrophy: What is the evidence? *Journal of Paediatrics and Child Health*, doi:10.1111/jpc.12177.

This review examined the evidence for non-surgical interventions for preventing scoliosis and the need for scoliosis surgery in children with Duchenne muscular dystrophy (DMD. Thirteen studies were identified and critically appraised independently by two reviewers. The included studies examined spinal orthoses and steroid therapy. There were no studies with high levels of evidence (randomised or other controlled trials). The studies with the highest level of evidence were non-randomised experimental trials. There is some evidence that children with DMD who receive steroid therapy might have delayed onset of scoliosis, but more evidence is required about the long-term risks versus benefits of this intervention. There is weak evidence that spinal orthoses do not prevent and only minimally delay the onset of scoliosis.

HARVEY, A., RANDALL, M., REID, S. M., LEE, K., IMMS, C., RODDA, J., ELDRIDGE, B. & REDDIHOUGH, D. S. 2013b. Children with cerebral palsy and periventricular white matter injury: does gestational age affect functional outcome? *Research in Developmental Disabilities*, 34, 2500-2506.

Functional profiles and movement disorder patterns in children aged 4–12 years with cerebral palsy (CP) and periventricular white matter injury (PWMI) born >34 weeks gestation were compared with those born earlier. Functional profiles were determined using the Gross Motor Function Classification System (GMFCS), Manual Abilities Classification System (MACS), Communication Function Classification System (CFCS), Functional Mobility Scale (FMS) and Bimanual Fine Motor Function (BFMF). Movement disorder and topography were classified using the Surveillance of Cerebral Palsy in Europe (SCPE) classification. 49 children born >34 weeks and 60 children born ≤34 weeks were recruited. Children with CP and PWMI born >34 weeks gestation were found to have milder limitations in gross motor function, mobility, manual ability and communication compared with those born earlier.

RANDALL, M., HARVEY, A., IMMS, C., LEE, K. & REID, S. 2013. Reliable classification of functional profiles and movement disorders of children with cerebral palsy. *Physical and Occupational Therapy In Pediatrics*, 33, 342-352.

The inter-rater reliability of four tools: the Communication Function Classification System (CFCS), Bimanual Fine Motor Function (BFMF), Surveillance of Cerebral Palsy in Europe (SCPE) classification tree, and Gross Motor Function Classification System (GMFCS) were examined in children with cerebral palsy (CP) and periventricular white matter injury (PWMI) aged 4–11 years. Twenty children were assessed by two raters using the four tools. In addition parents undertook ratings on the Manual Ability Classification System (MACS). The study found that these four tools are reasonably robust supporting their routine use along with the MACS in clinical and research applications.

REDDIHOUGH, D., JIANG, B., LANIGAN, A., REID, S., WALSTAB, J. & DAVIS, E. 2013. Social outcomes of young adults with cerebral palsy. *Journal of Intellectual and Developmental Disability*, DOI: 10.3109/13668250.2013.788690

Improvements in paediatric care of children with cerebral palsy (CP) have extended the expectation of achieving adulthood to 90%. Young adults aged 20 – 30 years with CP (n= 335) were compared to a population-based control group (n= 2,152) of the same age. Motor function, self-care abilities, educational level, and social outcomes were determined by questionnaire. Half the study group walked independently, but only 35.5% were independent in self-care. In comparison to their peers without disability, the study group's highest educational level was lower (p< .0001), as were rates of employment (36.3% compared with 80%),

they were more likely to be living with parents (80% compared with 21%), to be single, and to have limited financial resources. Young adults with CP are functionally and socially disadvantaged in contrast with their peers without disability. The examined variables contribute to these outcomes but are not solely responsible.

REID, S. M., WALSTAB, J. E., CHONG, D., WESTBURY, C. & REDDIHOUGH, D. S. 2013b. Secondary effects of botulinum toxin injections into the salivary glands for the management of paediatric drooling. *Journal of Craniofacial Surgery*, 24, 28-33.

The secondary benefits and side effects of botulinum toxin-A injections into the salivary glands in children with developmental disability were assessed to discover whether these effects are related to reduction in drooling. Twenty-six children were injected. The Drooling Impact Scale and a secondary effects questionnaire covering aspects of eating, speech, saliva management, and sleep, were administered to the main carer at specific times pre and post injection. Evidence of improvement was seen over the first four weeks post injection for the entire group with respect to drooling, eating, speech, and sleep, but not saliva management. Conversely, a minority of families reported worsening of eating skills and this was directly related to lack of improvement in drooling. Since a minority of children unpredictably experience temporary side effects after botulinum toxin injections into the salivary glands, swallowing function and nutritional status should be taken into account before proceeding with treatment.

RIESS, S., REDDIHOUGH, D. S., HOWELL, K. B., DAGIA, C., JAEKEN, J., MATTHIJS, G. & YAPLITO-LEE, J. 2013. ALG3-CDG (CDG-Id): Clinical, biochemical and molecular findings in two siblings. *Molecular Genetics and Metabolism*, doi.org/10.1016/j.ymgme.2013.05.020.

This paper describes two Vietnamese siblings with a particular type of congenital disorder of glycosylation, ALG3-CDG (CDG-Id), confirmed on molecular testing. As far as we are aware, they are the oldest reported patients in the literature at 15 and 21 years. They share similar clinical features with previously reported patients including facial dysmorphism, severe psychomotor retardation, microcephaly, seizures, and gastrointestinal symptoms. Furthermore, our sibling pair highlights the intrafamilial variability, the natural clinical course of ALG3-CDG (CDG-Id) and the benefit of reassessing patients with undiagnosed and complex syndromes, particularly when they present with neurological deterioration.

TERRETT, G., WHITE, R. & SPRECKLEY, M. 2013. A preliminary evaluation of the parent-child Mother Goose program in relation to children's language and parenting stress. *Journal of Early Childhood Research*, 11, 16-26.

A three year evaluation of the Parent-Child Mother Goose program (P-CMG), as provided by Uncle Bobs Childhood Development Cenntre in the community, was completed. There was a partnership between Australian Catholic University and Uncle Bobs with the University providing psychology students to collect data and the Uncle Bobs Centre providing the program. Data was also collected from community play groups which acted as a control group. The evaluation founds that children's expressive communication skills improved if they attended the P-CMG program as opposed to attending a community play group.

WILLIAMS, K., PERKINS, D., WHEELER, D., HAYEN, A. & BAYL, V. 2013. Can questions about social interaction correctly identify preschool aged children with autism. *Journal of Paediatrics and Child Health*, 49, E167-74.

Diagnostic accuracy of a questionnaire developed to assess social development (SIQ) in preschool children was assessed. Parents of 108 children with ASD, speech and language disorders, or 'developmental concerns', recruited from a clinical developmental assessment and community child health service, completed the SIQ, and also a Childhood Autism Rating Scale (CARS) assessment. The study found that the SIQ may assist clinicians in assessing social development and in making decisions about referral for autism assessment. Evaluation of the SIQ at the point of entry to a clinical service is still needed.

BOLCH, C. E., DAVIS, P. G., UMSTAD, M. P. & FISHER, J. R. 2012. Multiple birth families with children with special needs: a qualitative investigation of mothers' experiences. *Twin Research and Human Genetics*, 15, 503-15.

An exploratory study using the qualitative technique of thematic analysis to describe and interpret the experiences of 10 mothers of prematurely born multiple birth children with diverse special needs was completed. Most mothers experienced protracted concern over one or more babies' survival during pregnancy, and prescribed bed rest was frequently associated with increased anxiety and other adverse psychological effects. The contrast with experiences of mothers of healthy, term singletons caused considerable distress. Feelings of detachment and unreality were common in the immediate postpartum period, possibly due to transient depersonalization. Having more than one newborn created practical and psychological problems during the neonatal period, particularly when infants were separated due to differences in medical status. Mothers often felt guilty, particularly regarding inequality of care and attention they were able to provide to each child. This was especially problematic for multiples discordant for special needs status. Serious maternal mental health difficulties were common but not universal. Available formal supports were generally perceived as inadequate, addressing some, but not all, of the mothers' needs. Further work is needed to advance understanding of the relationships between mothers and their multiples, and to explore the implications of special needs within multiple birth families.

CONTOPOULOS-IOANNIDIS, D., SETO, I., HAMM, M., THOMSON, D., HARTLING, L., IOANNIDIS, J., CURTIS, S., CONSTANTIN, E., BATMANABANE, G., KLASSEN, T. & WILLIAMS, K. 2012. Empirical evaluation of age groups and age-subgroup analyses in pediatric randomized trials and pediatric meta-analyses. *Pediatrics* 129, S161-S184.

The age ranges of children, and age-subgroup analyses thereof, reported in recent pediatric randomized clinical trials (RCTs) and meta-analyses was investigated. The authors screened 24 RCTs published in Pediatrics during the first 6 months of 2011, 188 pediatric RCTs published in 2007 in the Cochrane Central Register of Controlled Trials; and 48 pediatric meta-analyses published in the Cochrane Database of Systematic Reviews in 2011. There was large variability in the age ranges and age-subgroups of children included in recent pediatric trials and meta-analyses. Despite the limited available data, some age-subgroup differences were noted. The rationale for the selection of particular age-subgroups deserves further study.

MCMULLAN, S., CHIN, R., FROUDE, E. & IMMS, C. 2012. Prospective study of the participation patterns of Grade 6 and Year 8 students in Victoria, Australia in activities outside of school. *Australian Occupational Therapy Journal*, 59, 197-208.

Positive participation outcomes are deemed the ultimate goal of health care and specifically of occupational therapy. This study investigated the participation of Grade 6 and Year 8 Victorian students in activities outside school and explored

differences between genders and between students in different year levels. Secondarily, we began to establish Australian normative data on the Children's Assessment of Participation and Enjoyment and Preferences for Activities of Children. The study recruited 84 students from a random selection of public schools. Participation was measured using the Children's Assessment of Participation and Enjoyment (CAPE) and Preferences for Activities of Children (PAC) questionnaires. Differences between year levels were only evident for participation in recreational and Active Physical activities. Grade 6 students did more activities, more intensely than Year 8 students, but with no difference in enjoyment. Gender differences were evident in the participation patterns within Social, Skill-Based and Self-Improvement activities. The findings suggested that gender was a more important influence on participation patterns than a 2-year age gap, with participation patterns being relatively stable between Grade 6 and Year 8.

WILLIAMS, K. & MARRAFFA, C. 2012. No evidence yet to support omega-3 fatty acids as a treatment for autism. *Journal of Paediatrics and Child Health*, 48, 534-536.

The evidence for Omega-3 as a treatment for autism spectrum disorders (ASD) was presented in this commentary. At the time of the review there were only two small studies with a total of 40 children with results available. The review found that there is no evidence that omega-3 fatty acids supplementation is effective for improving core or associated symptoms of ASD. A trend towards improvement of hyperactivity symptoms has been identified but not yet confirmed. Results of ongoing trials are awaited.

PAPERS USING THE VCPR TO RECRUIT

BOYD, R. N., JORDAN, R., PAREEZER, L., MOODIE, A., FINN, C., LUTHER, B., ARNFIELD, E., PYM, A., CRAVEN, A., BEALL, P., WEIR, K., KENTISH, M., WYNTER, M., WARE, R., FAHEY, M., RAWICKI, B., MCKINLAY, L. & GUZZETTA, A. 2013. Australian Cerebral Palsy Child Study: Protocol of a prospective population based study of motor and brain development of preschool aged children with cerebral palsy. *BMC Neurology,* 13, 57.

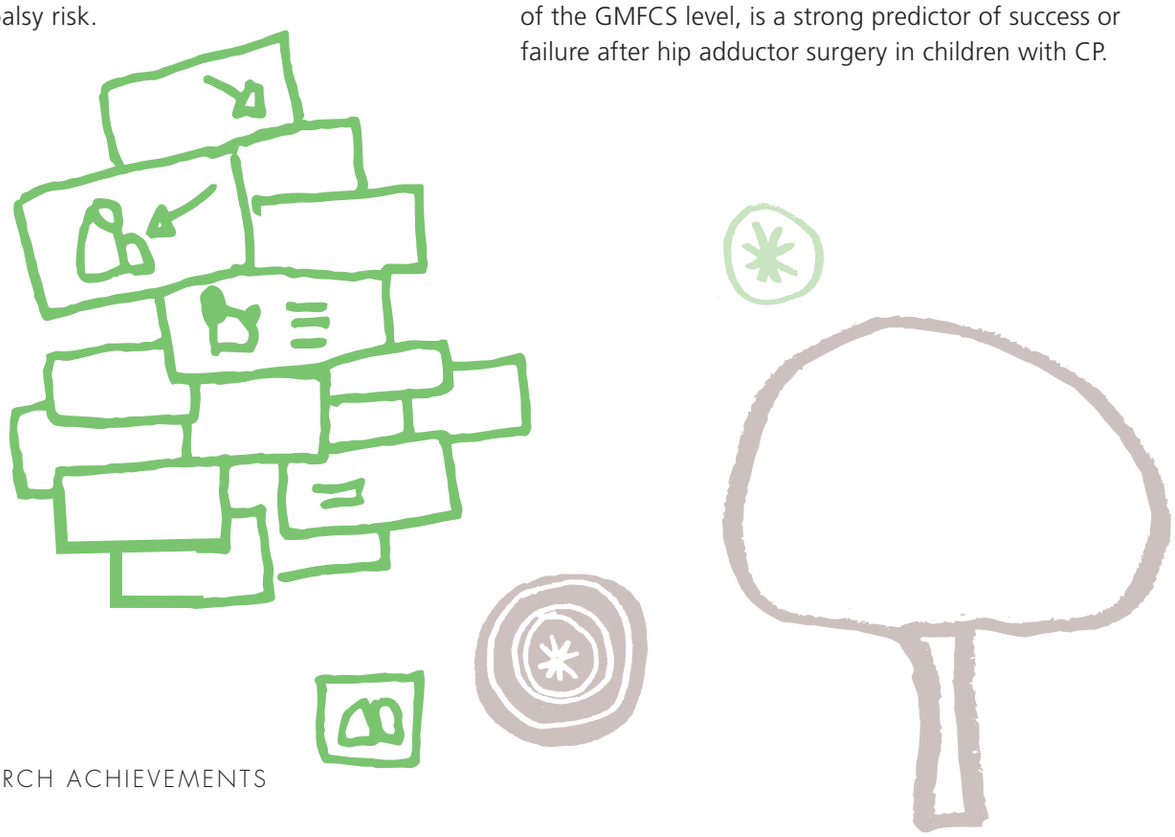
A study protocol to assess the pathway(s) to motor outcome from diagnosis at 18 months corrected age (c.a.) to outcome at 5 years in relation to the nature of the brain lesion (using structural magnetic resonance imaging (MRI)) is presented. It aims to recruit a total of 240 children diagnosed with CP born in Victoria (birth years 2004 and 2005) and Queensland (birth years 2006–2009). Outcomes include gross motor function (GMFM-66 & GMFM-88), Gross Motor Function Classification System (GMFCS); musculoskeletal development (hip displacement, spasticity, muscle contracture), upper limb function (Manual Ability Classification System), communication difficulties using Communication and Symbolic Behaviour Scales-Developmental Profile (CSBS-DP), participation using the Paediatric Evaluation of Disability Inventory (PEDI), parent reported quality of life and classification of medical and allied health resource use and determination of the aetiology of CP using clinical evaluation combined with MRI. The relationship between the pathways to motor outcome and the nature of the brain lesion will be analysed.

O'CALLAGHAN, M. E., MACLENNAN, A. H., GIBSON, C. S., MCMICHAEL, G. L., HAAN, E. A., BROADBENT, J. L., BAGHURST, P. A., GOLDWATER, P. N., DEKKER, G. A. & AUSTRALIAN COLLABORATIVE CEREBRAL PALSY RESEARCH GROUP 2013. Genetic and clinical contributions to cerebral palsy: A multi-variable analysis. *Journal of Paediatrics and Child Health*, 49, 575-581.

The association between single nucleotide polymorphism (SNP) with cerebral palsy were examined and the SNP–SNP and SNP–maternal infection interactions as contributors to cerebral palsy assessed. Thirty-nine candidate SNPs were genotyped in both mother and child. Data linkage to perinatal notes and cerebral palsy registers was performed with a supplementary maternal pregnancy questionnaire. History of known maternal infection during pregnancy was extracted from perinatal databases. The study found that maternal and child inducible nitric oxide synthase SNPs are associated with reduced risk of cerebral palsy in infants born very preterm. There was no evidence for statistically significant SNP–SNP or SNP–maternal infection interactions as modulators of cerebral palsy risk.

SHORE, B., YU, X., DESAI, S., SELBER, S., WOLFE, R. & GRAHAM, H. 2012. Adductor surgery to prevent hip displacement in children with cerebral palsy: The predictive role of the gross motor function classification system. *Journal of Bone and Joint Surgery*, 94, 326-334.

The relationship between walking ability, as determined with use of the Gross Motor Function Classification System (GMFCS), and the outcome of hip adductor surgery used to prevent hip displacement in children with cerebral palsy (CP) was evaluated. Records of 330 children with CP whose index surgery was bilateral hip adductor releases were reviewed. "Success" was defined as the absence of subsequent surgical procedures during the study period and a hip migration percentage of <50% in both hips at the time of follow-up. One hundred and six children (32%) met these criteria for success. The success rate was 94% (thirty-one of thirty-three) in children at a GMFCS level of II, 49% (twenty-seven of fifty-five) in children at a level of III, 27% (twenty-eight of 103) in children at a level of IV, and 14% (twenty of 139) in children at a level of V. Walking ability, as defined with use of the GMFCS level, is a strong predictor of success or failure after hip adductor surgery in children with CP.



RESEARCH RESOURCES

THE VICTORIAN CEREBRAL PALSY REGISTER

The Victorian Cerebral Palsy Register (VCPR) is a major research and planning data base. There were 5117 individuals born after 1970 who were registered at the end of 2013. The VCPR is the fundamental building block on which research and better practice is being built. Not only is the VCPR an invaluable resource for describing the prevalence, trends in prevalence, and characteristics of individuals with cerebral palsy in the Victorian population, but it facilitates important research investigating the causes of cerebral palsy and strategies for achieving the best outcomes for individuals with cerebral palsy and their families. The VCPR provides a very important reference framework for organisations working with people with cerebral palsy, researchers, planners and policy makers.

Over 2013 there has been:

1. Continued growth in registered children from 4950 to 5117, that is, 167 new cases

2. 9 publications in refereed journals and one publication available as an early online version

3. 14 new and ongoing projects using the VCPR, both with campus researchers and other researchers as lead investigators, and including four as PhD studies

4. Collaborations with universities and other organisations to complete research based on the register (eg Latrobe University, University of Melbourne, Monash University, Cerebral Palsy Alliance, NSW, Australian Catholic University, University of Notre Dame, Consultative Council on Perinatal and Paediatric Mortality and Morbidity).

5. Ongoing contribution of Victorian CP data to the Australian Cerebral Palsy Register (ACPR Group. The 2013 Report of the Australian Cerebral Palsy Register, Birth Years 1993-2006.)

6. Increased awareness of the CP Register internationally.

7. Improved understanding of cerebral palsy (trends in prevalence, patterns of brain abnormality on MRI, causal pathways), improved understanding of co-morbidities (cognition, speech and communication, orthopaedic problems), and outcomes of treatment (saliva control).

Key publications from the Cerebral Palsy Register are presented in more detail in the relevant sections above.

VICTORIAN PRADER-WILLI SYNDROME REGISTER

The Victorian Prader-Willi syndrome Register (VPWSR) is managed by Tess Lionti and has been running full-time for over 6 years and has gained tremendous support from families of children with PWS in Victoria. The aim of the VPWSR is to add to our understanding of the incidence, morbidity and mortality of the condition, thereby improving the quality of life for the young people with PWS and their families. The Register stores information about children with PWS either born, living and/or receiving service in Victoria. Data collection enables research based on all aspects of PWS, and assists in answering many vital questions regarding PWS.

At 31st December 2013, there were 183 individuals known to the Register (160 of whom were born in Victoria), with ages ranging from 1-63 years. We have increasing numbers of families who have consented for the registration of their child with PWS. To date, 72 families have consented and receive 3-yearly questionnaires about the person with PWS.

In May 2013, the VPWSR was presented as part of a PWS-specific Grand Rounds at the Melbourne Royal Children's Hospital. In July 2013, Tess Lionti travelled to Cambridge University in England to present data from the Victorian Prader-Willi Syndrome Register. The presentation was well received and was great for raising international awareness of the Register and networking with key international PWS researchers.

The amount of data available to the VPWSR has increased significantly over the past year and a new publication is in progress which describes the profile of individuals with PWS in Victoria.

STUDENTS & PARTNERSHIPS

PHD STUDENTS

SUE REID (UoM) (Awarded)
Topic: Cerebral palsy in Victoria: a population-based study
Supervisors: Dinah Reddihough, John Carlin

CHRISTIE BOLCH (Awarded)
Topic: The MultiQOL Study: An investigation into the quality of life of parents of multiple birth children with and without developmental disabilities
Supervisors: Jane Fisher, Dinah Reddihough, Mark Umstad

CRISTINA MEI (Completed being marked)
Topic: Speech and language in children with cerebral palsy
Supervisors: Sheena Reilly, Angela Morgan, Dinah Reddihough, Fiona Mensah

SUSAN WOOLFENDEN (Continuing, Part-time)
Topic: Inequity in Developmental Vulnerability, its determinants and the role of access to prevention and early intervention services.
Supervisors: Assoc Prof Lynn Kemp; Prof Valsa Eapen; Prof Katrina Williams

AMANDA BRIGNELL (Commenced 2013, Full-time)
Topic: Speech and language in autism
Supervisors: Angela Morgan, Katrina Williams

ELAINE MEEHAN (Commenced 2013, Full-time)
Topic: Cerebral Palsy Health services research
Supervisors: Dinah Reddihough, Katrina Williams, Michael Coory, Gary Freed, Sue Reid

NEDA TAGHIZADEH (Commenced 2013, Part-time)
Topic: Anaesthetics and preoperative care of children with ASD

REBECCA MITCHELL
(Maternity leave, Awaiting commencement)
Topic: Developmental outcomes of tuberous sclerosis
Supervisors: Katrina Williams, Simon Harvey

PARTNERSHIPS

During 2012-2013 Solve@RCH has developed new and maintained long-standing partnerships and collaborations with:

1. AUSTRALIAN CATHOLIC UNIVERSITY
Prof Christine Imms for multiple cerebral palsy projects including the Cerebral Palsy Check up program, the ACU funded multicentre randomised controlled trials of upper limb splinting for children with cerebral palsy and the Centre for Research Excellence in Cerebral Palsy

2. NOTRE DAME UNIVERSITY, SCHOOL OF MEDICINE
Prof Nadia Badawi, multiple CP projects including the Centre for Research Excellence in Cerebral Palsy and stem cell trial

3. DEAKIN UNIVERSITY
Prof Robert Carter, the Centre for Research Excellence in Cerebral Palsy.
Prof Nicole Rhinehart, multiple autism projects

4. UNIVERSITY OF WESTERN AUSTRALIA
Prof Eve Blair, CP projects including the Centre for Research Excellence in Cerebral Palsy and stem cell trial

5. THE ROYAL CHILDREN'S HOSPITAL BRISBANE
Collaborators in a multicentre collaborative study to investigate the use of stem cells in children with cerebral palsy. Dr Honey Heussleur, Angelman Sydnrome and autism projects

6. LATROBE UNIVERSITY, VICTORIA
Dr Paul Junor, Department of Electronic Engineering.
Prof Cheryl Dissanyake, The Olga Tennison Autism Research Centre

7. MACQUARIE UNIVERSITY, NSW
A/Prof Mark Carter, Macquarie University Special Education Centre (MUSEC)

8. AUSTRALASIAN SOCIETY FOR AUTISM RESEARCH (ASFAR) (NATIONAL)
Collaborating with researchers from WA, Victoria, NSW, Queensland, SA

9. UNIVERSITY OF ALBERTA, EDMONTON (INTERNATIONAL)
Cochrane Child Health Field, Ms Denise Thomas & Dr Lisa Hartling

10. STAR (INTERNATIONAL)
Prof Terry Klassen (Canada) & Professor Martin Offringa (Canada)

11. NEWCASTLE UNIVERSITY (UK)
Prof Helen Maconachie &
Prof Ann Le Couteur

12. BARWON HEALTH AND DEAKIN UNIVERSITY
Dr David Fuller & A/Prof Peter Vuillermin

13. NEUROLOGY (RCH, AUSTIN HOSPITAL)
Autism, Tuberous Sclerosis and Angelman Syndrome, Dr Simon Harvey & Prof Ingrid Scheffer

14. UNSW AND SYDNEY CHILDREN'S HOSPITAL NETWORK (NSW)
Developmental surveillance and prognosis of ASD, Prof Valsa Eapen, Dr Susan Woolfenden, Dr Vivian Bayl, Dr Vanessa Sarkozy

15. COCHRANE PROGNOSIS METHOD GROUP (INTERNATIONAL)
Prof Doug Altman (UK), Prof Karel Moons (The Netherlands), Dr Richard Riley (UK), Dr Jill Hayden (Canada)

16. MONASH UNIVERSITIES (VICTORIA) & MONASH MEDICAL CENTRE
Ongoing collaboration with a number of groups including Medical Imaging and the Victorian Paediatric Rehabilitation Service

Prof Frada Burnstein, Autism information technology platform development

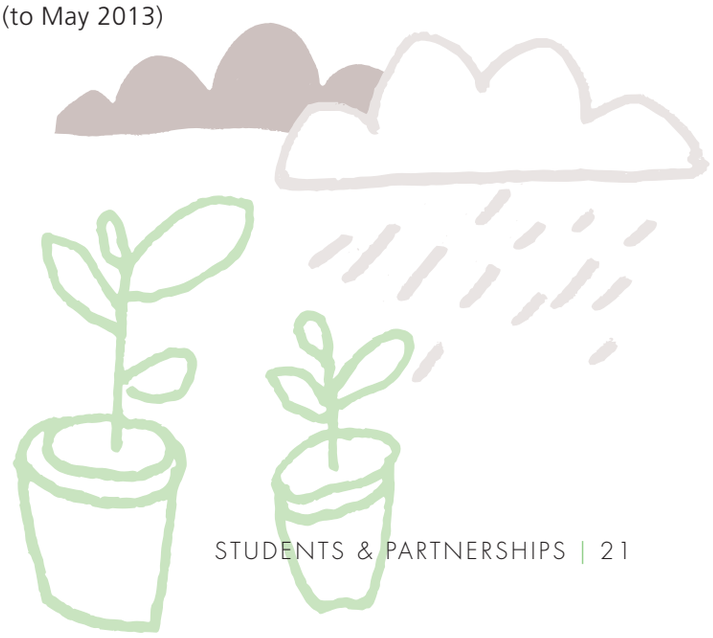
Dr Michael Fahey and Professor Euan Wallace, a multicentre collaborative study to investigate the use of stem cells in children with cerebral palsy

17. CANCHILD (MCMASTER UNIVERSITY, CANADA) HAVE BEEN PARTICULARLY HELPFUL.
Dr Adrienne Harvey is an "International Collaborator" with CanChild. Professor Peter Rosenbaum is an associate investigator on the Centre for Research Excellence in Cerebral Palsy.

18. COMMUNITY ORGANISATIONS
Scope Victoria, Yooralla Society of Victoria, Amaze (Autism Victoria), Autism SA, Aspect

19. THE CEREBRAL PALSY ALLIANCE, NEW SOUTH WALES
Co-funds the preliminary investigation into the therapeutic benefits of stem cells in cerebral palsy. Together with other state cerebral palsy registers, the Cerebral Palsy Alliance also provides supports the Australian Cerebral Palsy Register, in which the Victorian Cerebral Palsy Register collaborates.

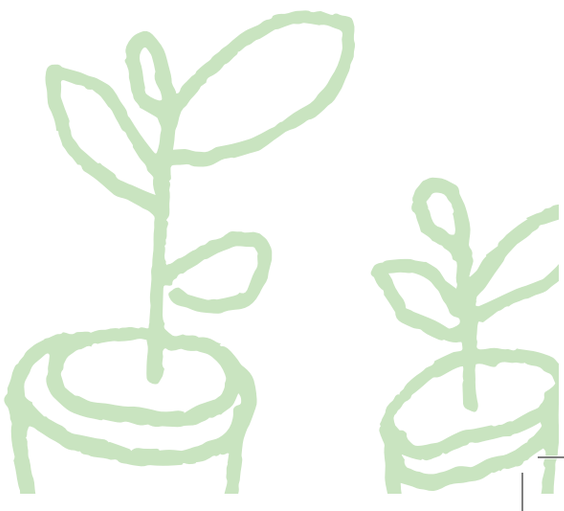
MEMBERSHIP OF BOARDS AND ADVISORY PANELS
Australian Autism Advisory Board (AAB) (Katrina Williams)
Amaze Board (Katrina Williams)
Yooralla Board Member (Dinah Reddihough) (to May 2013)



FUNDING

COMPETITIVE AND GOVERNMENT RESEARCH FUNDING 2012 AND MORE RECENT

YEAR	FUNDING AGENCY	INVESTIGATORS	TOPIC	AMOUNT
2014-18	National Health & Medical Research Council	Reddihough D, Graham HK, Imms C, Badawi N, Waters E, Blair E, Carter R	A Centre for Research Excellence in Cerebral Palsy.	$2,497,003
2014-2016	National Health & Medical Research Council. Project Grant	Reid S, Dagia C	Understanding white matter injury in term-born children with cerebral palsy	$188,642
2014-	National Health & Medical Research Council. Early Career Fellowship	Reid S	Improving our understanding of the causes of cerebral palsy	$304,596
2013	University of Melbourne Staff Engagement Grant	Davis E, Waters E, Jones K, Reddihough D, Williams K, Herrman H, McEvoy M*, McGorry E.	Promoting the mental health and wellbeing of parents of children and adolescents with a disability: Hearing the Voices of Parents	$10,000
2013	The Marian & E.H.Flack Trust	Reddihough, D	Improving control of movement in children with cerebral palsy	$46,015
2013	Clinical Sciences Theme grant, Murdoch Childrens Research Institute	Reid, S.	MRI patterns and causal pathways to cerebral palsy	$25,000
2013	Foundation for Children	Craig J, Crompton K, Reddihough D	Can we predict cerebral palsy at birth?	$79,765
2013	The Ian Potter Foundation	Reddihough D	Risk factors for cerebral palsy	$100,000
2012- 13	The John T Reid Charitable Trust	Reddihough D	Preliminary investigation of the therapeutic potential of human umbilical cord stem cells in cerebral palsy	$100,000



YEAR	FUNDING AGENCY	INVESTIGATORS	TOPIC	AMOUNT
2012-13	Cerebral palsy International Research Foundation	Hoare B, Crichton A, Harvey A	Cognition and bimanual upper limb performance in children with hemiplegic cerebral palsy	$100,000
2012-13	The Cerebral Palsy Alliance	Reddihough D	Preliminary investigation of the therapeutic potential of human umbilical cord stem cells in cerebral palsy	$100,000
2011-15	ARC Linkage Grant	Carter M, Stephenson J, Williams K, Clark TR, Costley DM, Martin J.	The efficacy of models for educational service delivery for students with autism spectrum disorders.	$348,446
2011-13	NH&MRC Partnership Grant	Eapen V, Williams K, Jalaludin B, Dissanayake C, Woolfenden S.	Universal surveillance and early identification of developmental disorders.	$650,598
2009-13	Department of Human Services	Reddihough D	The Victorian Cerebral Palsy Register	$250,000
2012	Practical Design Funding for National Disability Insurance Scheme, Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA)	Davis E; Williams K; Waters E; Scheinberg A; Reddihough D.	Developing training guidelines for local area co-ordinators	$122,405
2012	Practical Design Funding for National Disability Insurance Scheme, FaHCSIA	Davis E; Williams K; Waters E; Herrman H; Reddihough D; Fisher J.	Developing a resource to support mental health needs of carers of children and young people	$157,801.
TOTAL				$5,080,271

*From Melbourne Playback Theatre Company

OTHER RESEARCH FUNDING

YEARS	TRUST / FOUNDATION	FUNDING FOR	FUNDING RECEIVED
2012	The Lorenzo and Pamela Galli Charitable Trust	MRI studies of cerebral palsy, stem cell research	$150,000
2012-2013[1]	Waverley Auxiliary	Developing training for parents/carers and professionals	$12,000
2012-2013[1]	Doo-Bees and Trailblazers Auxiliaries	Prader-Willi Syndrome Register	$30,000
2012 2013	The Victorian Medical Insurance Agency	Five and 10 year follow up of children with cerebral palsy	$44,737 $22,367
2010-2012	William & Vera Houston Memorial Trust Fund	School age outcomes of children with moderate-severe hypoxic-ischemic encephalopathy	$61,184
TOTAL			$320,288

1. Financial Year

DONATIONS

In additions, donations are made through work place giving and named or anonymous donations. These monies are spent on research related expenses.

STAFF DECEMBER 2013

STAFF INVOLVED IN TRAINING OR RESEARCH AND/OR SUPPORTED BY RESEARCH FUNDING

EMPLOYER		STAFF MEMBER	WORK FRACTION
RCH	Medical	Professor Katrina Williams[1]	1.0
	Medical	Dr Catherine Marraffa	0.4
	Medical	Professor Dinah Reddihough[1]	1.0
	Medical	Dr Margaret Rowell	0.2
	Medical	Dr Giuliana Antolovich	0.4
	Medical	Dr Louise Baker (2013)	1.0
	Medical	Dr Kate Milner (to end 2012)	0.5
	Medical	Dr Monica Cooper (2013)	0.5
	Medical	Dr Rebecca Quinn (2013)	0.5
	Psychology	Ms Margaret Charlton	0.3
	Nursing	Ms Marijke Mitchell	0.6
	Administration	Ms Elizabeth Cassidy	1.0
Victorian Paediatric Rehabilitation Service (VPRS)	Medical	Dr Adam Scheinberg	1.0
	PT	Dr Adrienne Harvey[2]	0.9
Uncle Bobs Child Development Centre	PT	Ms Michèle Spreckley (Manager)	1.0
MCRI Developmental Disability & Rehabilitation Research Group	Research	Ms. Sue Reid	1.0
	Research	Ms Tess Lionti	1.0
	Research	Mr Steven Kloprogge (to end 2013)	0.4
	Research	Mrs Janet Walstab[3]	0.2
	Research	Ms Christine Westbury	0.4
	Research	Ms Elaine Meehan (PhD 2013)	0.4
	Research	Dr Kylie Crompton	0.6
	Research	Ms Molly O'Sullivan	0.4
UoM	OT	Dr Melinda Randall[1]	1.0
	Psychology	Dr Natalia Urios (mid to end 2013)	0.4
	SP	Ms Amanda Brignell (PhD 2013)	0.2
	Psychology	Mr Shawn Stephenson	1.0
	Administration	Ms Michelle Nelthropp	1.0

1. UoM and RCH
2. VPRS and RCH
3. Retired end of 2012

PT Physiotherapist
OT Occupational Therapist
SP Speech Pathologist

PUBLICATIONS 2009 - 2013

2013

1. Baikie, G., Ravikumara, M., Downs, J., Naseem, N., Wong, K., Percy, A., Lane, J., Weiss, B., Ellaway, C., Bathgate, K. & Leonard, H. Guidance in the management of gastroesophageal reflux disease, constipation and abdominal bloating in Rett syndrome. Journal of Pediatric Gastroenterology and Nutrition. 2013. DOI:

2. Boyd RN, Jordan R, Pareezer L, et al. Australian Cerebral Palsy Child Study: Protocol of a prospective population based study of motor and brain development of preschool aged children with cerebral palsy. BMC Neurology 2013; 13:57.

3. Davis E, Mackinnon A, Davern M, et al. Description and psychometric properties of the CP QOL-Teen: a quality of life questionnaire for adolescents with cerebral palsy. Res Dev Disabil 2013; 34:344-52

4. Davis, E., Gilson, K. M., Corr, L., Stevenson, S., Williams, K., Reddihough, D., Waters, E., Herrman, H. & Fisher, J. 2013. Enhancing Support for the mental health of parents and carers of children with disability Available: http://www.disabilitycareaustralia.gov.au/document/519

5. Corr L, Teo E, Ummer-Christian R, Davis E, Williams K, Reddihough D, Scheinberg A, Waters E. Developing training guidelines for local area coordinators working with children and young people with disability and their families 2013. Available from: http://www.disabilitycareaustralia.gov.au/sites/default/files/documents/Davis_PDF_LAC_project.pdf

6. Greenwood V, Crawford N, Walstab J, Reddihough DS. Immunisation coverage in children with cerebral palsy compared to the general population. J Paediatr Child Health 2013; 49:E137-E41.

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ADVISORY PANEL

The Advisory Panel has been energetic, strategic and has demonstrated great wisdom. Thanks to past members, new members and ongoing members.

BRUCE BONYHADY AM (CHAIRMAN)

Bruce Bonyhady is Chairman of Yooralla, Victoria's largest disability service provider, President of Philanthropy Australia and Deputy Chair of the Advisory Group to the Select Council of COAG on Disability Reform.

Bruce's background is in economics, funds management and insurance and his current roles include being Chairman of Acadian Asset Management Australia Ltd and a Director of Director of Dexus Wholesale Property Limited. Bruce has three adult children, two of whom have disabilities. In 2010 Bruce was made a Member of the Order of Australia for his services to people with disabilities and the community.

PROF GLENN BOWES

Glenn Bowes is Associate Dean (External Relations) for the Faculty of Medicine, Dentistry & Health Sciences at the University of Melbourne. A clinical academic specialising in adolescent and respiratory medicine, Glenn has had professorial appointments in the Department of Paediatrics of the Melbourne Medical School since 1991.

DR D ROBERT DICKENS

Robert Dickens is an Honorary Orthopaedic Surgeon and Consultant to the Department of Orthopaedics at the Royal Children's Hospital. He was previously the Head of the Department of Orthopaedics at the Royal Children's Hospital and worked for many years with Dinah Reddihough and the Department of Child Development and Rehabilitation (now known as Developmental Medicine), to assist children with disabilities.

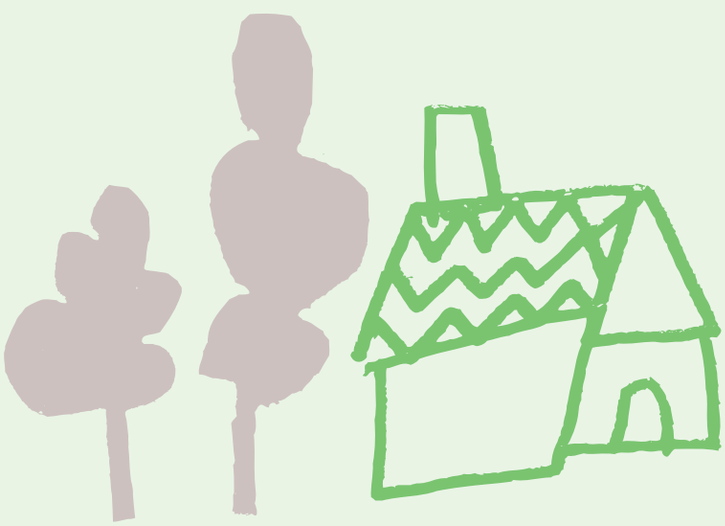
A/PROF ADAM SCHEINBERG

A/Prof Adam Scheinberg is a paediatric rehabilitation specialist who worked in Sydney at The Children's Hospital Westmead, before moving to Victoria in 2009 as the Statewide Medical Director of the Victorian Paediatric Rehabilitation Service (VPRS). The VPRS provides ambulatory rehabilitation services at eight sites around Victoria, and inpatient rehabilitation programs at Monash Children's and Royal Children's Hospitals. Information about the VPRS is at www.health.vic.gov.au/vprs/. Dr Scheinberg has an interest in translating research into clinical practice. He is an associate investigator on the Cerebral Palsy-CRE and Brain Recovery-CRE "Moving Ahead", and leads clinical research on Chronic Fatigue Syndrome funded by a Mason Foundation grant. He is the immediate past president of the Australasian Academy of Cerebral Palsy and Developmental Medicine.

PROF VICKI ANDERSON

Vicki is a Professor and Director of Psychology at the Royal Children's Hospital, and Director of Critical Care and Neuroscience Research at the Murdoch Childrens Research Institute. Her research group at the Royal Children's Hospital, the Australian Centre for Child Neuropsychological Studies (ACCNS), was established in 2000.

Vicki is consulting editor on a number of international journals including the Journal of the International Neuropsychological Society, Child Neuropsychology, Developmental Neuropsychology, and Developmental Neurorehabilitation. She has been Chair of the NHMRC Mental Health panel, a member of the NHMRC Assignors Academy and is a member of the NHMRC principle committee, the Australian Human Ethics Committee. She is a fellow of the Academy of Social Sciences of Australia and a fellow of the Australian Society for the Study of Brain Impairment.



MS SUE HUNT

Sue Hunt has worked up and down eastern Australia in senior executive positions in the arts industry for over 20 years, and held a string of board memberships across a huge variety of arts and government organisations. In July 2010, Sue returned to her home state of Victoria for the first time in over a decade to take up the position of Executive Director of The Royal Children's Hospital Foundation.

With a background as a stage manager and technical director for the Victoria State Opera, she became the General Manager of the Geelong Performing Arts Centre (1995-99) and was General Manager of the Queensland Theatre Company (1999-2003). She was subsequently Director of Performing Arts for the Sydney Opera House (2003-06), and then became the Founding CEO of CarriageWorks, Sydney's new home of contemporary arts and culture (2006 – 2010).

DR CATHERINE MARRAFFA

Catherine Marraffa is a developmental paediatrician with over 25 years of clinical experience in the disability field. She has cared for a large number of patients with a range of physical and intellectual disabilities who have been followed from early childhood to young adulthood. She has particular expertise in the diagnosis and management of children with autism. She has been invited to sit on many Victorian state government working parties since returning to Australia from the UK 18 years ago. During her time as chairman of the State Committee, Division of Paediatrics and Child Health, Royal Australasian College of Physicians (2004-2008), she focussed on improving services for children with disabilities in Victoria. She is a board member of the Olga Tennison Autism Research Centre at Latrobe University.

Research interests include the link between autism and bowel symptoms, autism and movement disturbance using the reach-to- grasp movements and current research involves examining the role of medication in children with autism.

MRS ANNE MCGEARY

Anne McGeary has been raising funds for the Royal Children's Hospital since 1994. She was a founding member of Ultimate Challenge Auxiliary, which was established to raise funds for the Department of Child Development and Rehabilitation (now known as Developmental Medicine). After 11 years she began another Auxiliary, Trailblazers Auxiliary. Anne's late brother had a disability and "my own path led me to Professor Dinah Reddihough and the wonderful work she does for children with disabilities". Anne is also a Director of a travel company.

MRS KATIE O'CALLAGHAN

Katie O'Callaghan is a parent of a child with cerebral palsy. She is a qualified occupational therapist, and holds a Graduate Diploma of Management, which she completed while working as an occupational therapist in rural Queensland, as well as an MBA from London.

Most of her professional work over the past 10 years has been in management, both as a General Manager and Human Resources Director in the community sector. Previous directorships include Ecumenical Community Housing and the Ecumenical Housing Trust and also as a Member of the Committee of Management of Ecumenical Housing Inc, which later became Melbourne Affordable Housing. She has also served on the Committee of Management at the Victorian Advocacy League for Individuals with a Disability (VALID), including three years as President.

PROF DINAH REDDIHOUGH, AO

Dinah Reddihough was Director of Developmental Medicine between 1986 and January 2011. Dinah is involved in the clinical care of children with disabilities, particularly young people with cerebral palsy and has developed a research program which is focused on gaining an improved understanding of the causes and outcomes of disabilities in childhood. She established the Victorian Cerebral Palsy Register in 1987 which is now one of the largest of its kind, and has had 46 projects resulting from it. Dinah has been awarded over $5 million in research grants and has over 120 refereed publications and book chapters.

Dinah's community involvement has included Medical Adviser to the Arthur Mardsen Whiting Sympathy Fund since 1995. She has chaired the Scientific sub-committee of the Apex Foundation since 1998 and was on the Board of Yooralla between 1986 and 2013. She was on the Wesley Mission Board of Management between 1989-2001.

Dinah launched the Australasian Academy of Cerebral Palsy and Developmental Medicine in 2001. This is a multidisciplinary group committed to advancing knowledge in the field of physical disability in childhood by conducting scientific meetings, promoting educational activities and fostering research. It hosts conferences at two yearly intervals. An oration has been named in honour of Dinah's foundation work.

MRS MARGERY SCHREPPEL

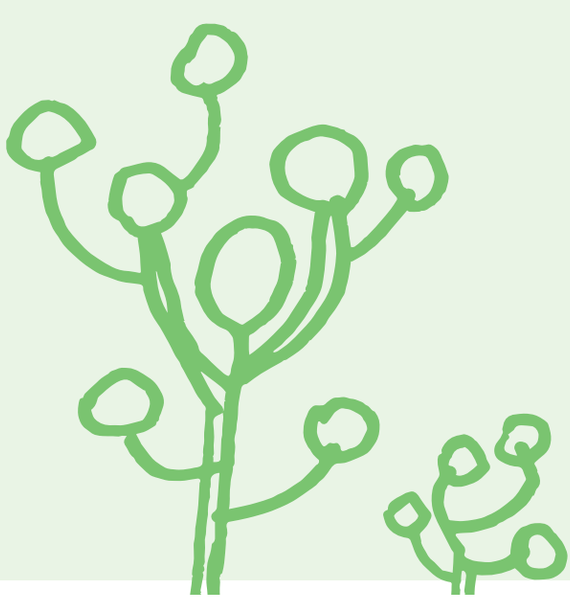
Margery Schreppel was a primary and junior secondary teacher at Caulfield Grammar School Elsternwick, many schools in London prior to retiring at Grimwade, Melbourne Church of England Grammar School. Margery has also owned two art galleries in Gippsland. Margery joined the RCH Waverley Auxiliary after retiring and has been raising funds for the Department of Developmental Medicine for twelve years.

MRS CHLOE SHORTEN

Chloe Shorten is a qualified public affairs manager and communications specialist with over 20 years experience in the profession, primarily dealing with issues management, media relations, corporate and marketing communications and stakeholder management. Chloe has excellent relationships with and management of key stakeholders including industry groups, communities, media, government, major corporate customers, legal practitioners, shareholders and board members. Chloe is passionate about using her skills to bring about research advances that will improve the lives of children with disabilities.

PROF KATRINA WILLIAMS

Katrina is a paediatrician and public health physician with an MSc in Community Child Health (University of London) and a PhD on the subject of epidemiology of autism spectrum disorders (University of Sydney). Katrina is an internationally recognised clinical epidemiologist and developmental medicine researcher. Katrina trained and worked as a Paediatrician in Sydney and London prior to her move to Melbourne, and is currently collaborating with colleagues in the UK, US, the Netherlands, Canada and across Australia to influence child health research methods and autism research. Katrina is also actively involved in initiatives that aim to improve clinical care, service delivery and inform policy for children with developmental disabilities. Appointed as the APEX Australia Professor of Developmental Medicine, and Director of Developmental Medicine, Katrina commenced her role at RCH and University of Melbourne at the end of January 2011.



NOTES

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FOR MORE INFORMATION ABOUT SOLVE@RCH PLEASE CONTACT: DEVELOPMENTAL MEDICINE
THE ROYAL CHILDREN'S HOSPITAL MELBOURNE 50 FLEMINGTON ROAD, PARKVILLE 3052 VICTORIA
T 61 3 9345 9823 / 9345 5898 **E** DEV.MED@RCH.ORG.AU **F** 9345 4848 WWW.RCH.ORG.AU/CDR
WWW.MCRI.EDU.AU/RESEARCH/THEMES/CCN/DEVELOPMENTAL-DISABILITY-AND-REHABILITATION-RESEARCH/