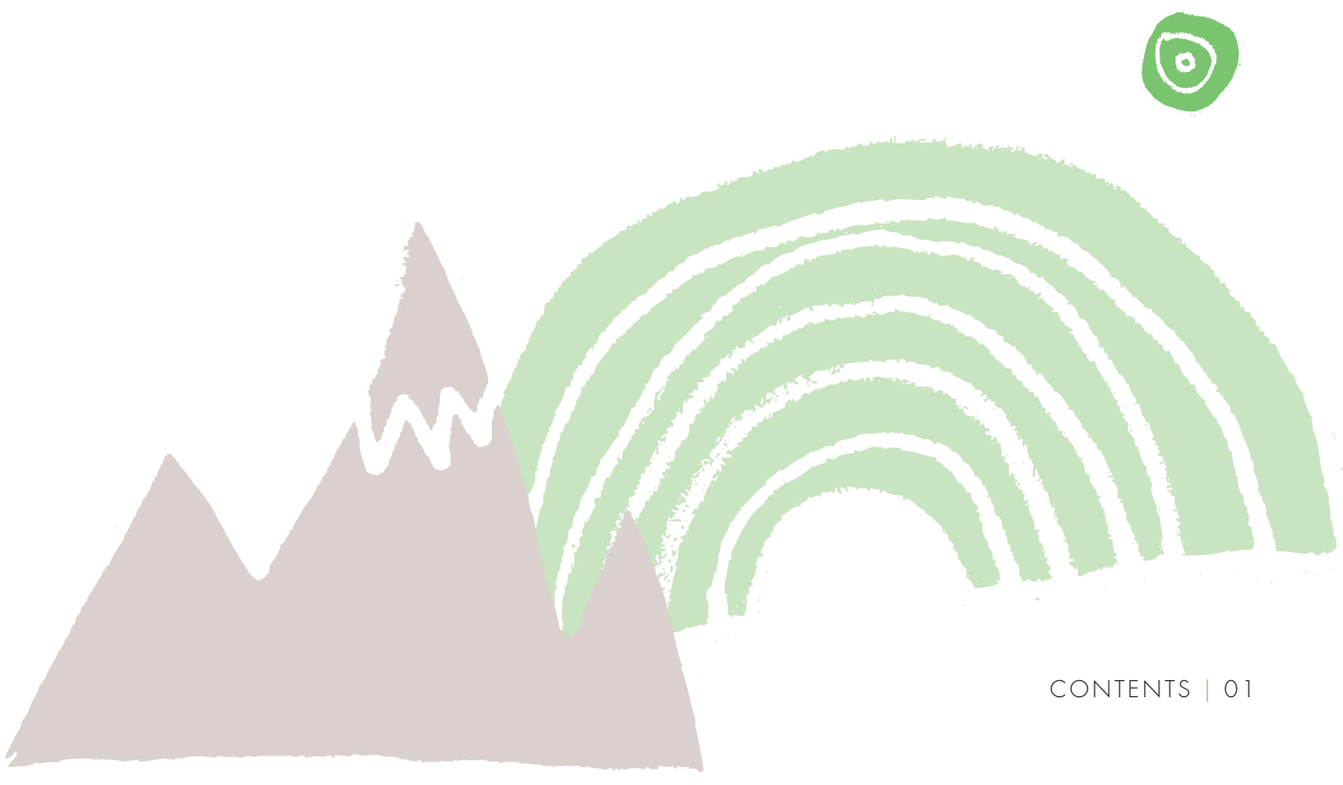
SOLVE@RCH ANNUAL REPORT

JANUARY 2014 – DECEMBER 2015

CONTENTS



CHAIR OF THE ADVISORY PANEL

In 2014 Solve@RCH reached the very significant milestone of 10 years since Professor Dinah Reddihough brought together a very small group or colleague and parents of children with disabilities to establish a centre for developmental medicine research. We were then honoured that Professor Sir Gustav Nossal formally launched Solve@RCH in 2006.

It is therefore an appropriate time to look back and reflect on more than 10 years of remarkable achievements.

In this short time, two new fully endowed chairs in Developmental Medicine have been created at The Royal Children's Hospital, Melbourne (RCH) – the Apex Australia Chair in Developmental Medicine held by Professor Katrina Williams and The Lorenzo and Pamela Galli Chair in Developmental Medicine held by Professor David Amor.

In 2015 The Apex Foundation for Research into Intellectual Disability (AFRID) received court approval to wind up its activities and gift its corpus to the RCH Foundation. This was matched by a very generous provision from the RCH Foundation. We are deeply indebted to the Trustees of AFRID for the confidence and trust they have shown.

In 2011 Professor Dinah Reddihough was awarded a Vice Chancellor's Fellowship from the University of Melbourne and in late 2013 she established Australia's first National Health and Medical and Research Council (NHMRC) Centre for Research Excellence (CRE) in Cerebral Palsy.

The CRE includes funding for 10 PhD students and so it is helping to build the next generation of leaders in cerebral palsy research. This is in addition to many other postgraduate students who have been attracted to developmental medicine as an area of vital research through Solve@RCH.

In 2011 Professor Katrina Williams became Director of the Department of Developmental Medicine at The Royal Children's Hospital. Since then competitive research funding and PhD supervision have grown, as have publications in high-impact, peer-reviewed journals.

None of this would have been possible without the commitment of Solve's clinicians and researchers to be world-best by striving for and attaining maximum research impact, and developing and leveraging key partnerships and collaborations. Nor would it have been possible without the support of strategic and visionary philanthropists. Going forward there is now a platform to make an even bigger impact in the lives of children with disabilities and their families to which Solve@RCH is dedicated.

Bruce Bonyhady AM
Chair, Solve@RCH Advisory Panel

EXECUTIVE SUMMARY

The past two years have been busy and productive with major achievements across research, training, clinical care and advocacy. The team has grown and continues to be highly motivated and to work in a well-integrated way across disciplines, organisations and clinical and research areas of expertise.

I'd like to thank all staff and our passionate and active Advisory Panel members, who are experts, consumers and fundraisers. Farewell to Enver Bajraszewski, Tess Lionti, Melinda Randall and Michelle Nelthropp who have retired or moved to new positions. Welcome to our 11 new staff (see Table 2). In particular we applaud the success of Dr Adrienne Harvey, who has been awarded a prestigious Melbourne Children's Campus Career Development Award, and our staff or students who have successfully completed higher degrees.

Professor Dinah Reddihough has led a collaboration of Australian and international expert colleagues to embark on the body of work funded as a Centre of Research Excellence Grant for Cerebral Palsy (CRE-CP) by the National Health and Medical and Research Council (NHMRC). A report of the many achievements stemming from this grant is provided on page 16. Thanks also to all the lead and co-investigators and partner organisations we are working with for NHMRC and ARC funded projects (see Table 1).

The search and appointment process for The Lorenzo and Pamela Galli Chair of Developmental Medicine, made possible by a generous donation, is nearly complete. The Apex Australia Foundation for Intellectual Disability Research has also partnered with The Royal Children's Hospital Foundation to endow The Apex Australia Chair of Developmental Medicine, which supports my continuing role.

We have built a new website that is the platform upon which our communication and training strategy is built. We are now reaching more than 1000 professionals, parents and people living with disability via our mailing list, and our online and face-to-face training was accessed by over 400 individuals over the past two years.

We have continued to publish in journals that are either top-tier for our areas of work or the most relevant for reaching clinicians we need to communicate with about our research and translation activities. We have continued to attract funding from competitive research grants, and also to be supported by government and philanthropic funders.

Our research databases continue to be a crucial platform for research, especially the Victorian Cerebral Palsy Register (VCPR), which is internationally recognised. In the past two years we have started new databases with the support of philanthropic funding and/or relationships with colleagues working at other sites. We now have a Neural Tube Defects Register (NTDR) and ethics approval to recruit for the Melton Developmental Differences Database (M3D); see pages 14 and 15 for more information.

The past two years have also seen us develop research partnerships with parents and carers of children and young people with a disability. We have also worked more closely with our bioethics and economics colleagues. This is to ensure we keep in sight the important social and financial implications of the work we are doing.

Everything we do is designed to assist children with developmental disabilities and their families. Some of our work will take longer to change the lives of children, but needs to be started now to help future generations. Other work will be ready to be incorporated into best practice, service development and policy as soon as it is finished. We are working towards the day when all children and families receive effective care that is tailored to their needs at the optimal time. The partnerships we're forming across sectors, specialties and disciplines will help us make the progress we need toward this goal.

Professor Katrina Williams
The Apex Australia Chair of Developmental Medicine, University of Melbourne; Director, Developmental Medicine, The Royal Children's Hospital

KEY SUPPORTERS & 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

PSA Professional Services Australia

Victoria State Government | Health and Human Services

Apex Foundation for Research into Intellectual Disability

Victorian Medical Insurance Agency

Department of Health and Human Services

ROYAL CHILDREN'S HOSPITAL FOUNDATION

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 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, and
- improve the way we provide care and services for children with disability and their families.

OBJECTIVES

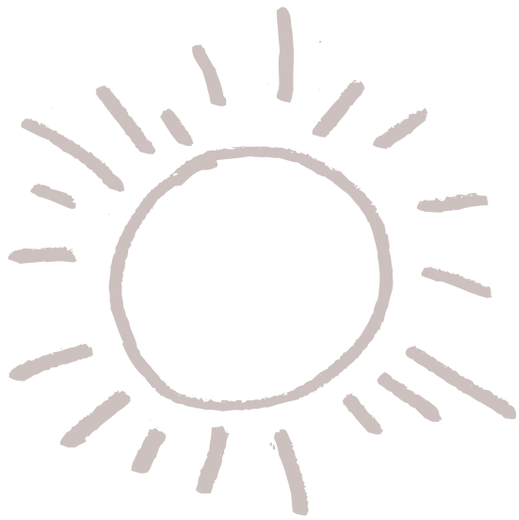
- Build developmental disability data resources.
- Work collaboratively with other organisations involved in the care of children with disabilities and relevant research organisations.
- Increase the future workforce of developmental disability clinician researchers and scientists.
- Raise the profile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

We are now a well-integrated clinical, research and training centre located at The Royal Children's Hospital (RCH), Melbourne, working with three campus partners: The University of Melbourne, RCH and the Murdoch Childrens Research Institute. Employees of all three institutions – now more than 50 in number – work as clinicians, clinician researchers, scientists and administrators. We have links to non-government services and other public sector services at both federal and state levels in health, education and community services. We are governed by the RCH professional and ethical standards and our own Advisory Panel. Our research work includes the breadth of developmental problems and disability and uses robust research methods to answer important questions (Figure 1). We are well connected to care and the community, which means we are ideally placed to translate evidence to practice and service delivery.

Figure 1. The types of research methods we use to answer important questions for all types of developmental difference.

Types of research and clinical domains	Autism and social communication disorders	Cerebral palsy and other physical disabilities	Intellectual disability and known genetic disorders
Biological science and genetics	What is the cause?		
Clinical science*	What are effective interventions? What does the future hold? Is the diagnosis accurate?		
Systematic review methods			
Population health and data science	How common is this? Are we making best use of health services?		

How did we get to where we are today? In 1986 the Department of Developmental Paediatrics (subsequently renamed Child Developmental and Rehabilitation and then further renamed Developmental Medicine) was formed at the RCH and Dinah Reddihough. Now a Professor at the University of Melbourne and a Member of the Order of Australia (AO), was appointed as the Director. Professor Reddihough engineered major growth in the clinical department and in research. In 2004 she formed the Centre of Developmental Disability Research because of the urgent need to increase knowledge about 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.

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 RCH Foundation. Professor Katrina Williams, a leader in autism research, was appointed both as the Chair and as Director of the Department of Developmental Medicine at the RCH.

Dinah was awarded a University of Melbourne Vice Chancellor's Fellowship in 2011. In 2012 we were able to formalise an existing training role for Developmental Medicine with the appointment of a training coordinator to leverage electronic communication and training opportunities. In 2013, The Lorenzo and Pamela Galli Foundation generously donated $5 million to endow The Lorenzo and Pamela Galli Chair in Developmental Medicine. The University of Melbourne also agreed to support an additional three years of funding to support Professor Reddihough's research, starting in 2015. During 2015 the Apex Foundation for Research into Intellectual Disability donated $2 million, which was supplemented by the RCH Foundation, to endow The Apex Australia Chair of Developmental Medicine.

The clinical work that we do has also changed in line with community needs and resources. In 2015 our clinical team, led by Drs Kate Thomson Bowe, Giuliana Antolovich, Adrienne Harvey and Ms Sacha Peterson, developed systems that will harness the potential of the electronic medical record for ensuring best clinical care and bridging a data gap that exists between clinical care and research.

All our research aims to minimise impairments, maximise activity and promote participation and wellbeing of children with developmental disability and their families. Many new research collaborations and partnerships have been established over the past two years, adding skills as well as financial resources to the efforts of the team. We are also increasingly providing research training, to equip the future workforce with skills to ensure evidence-based health care and important discoveries in the years to come.

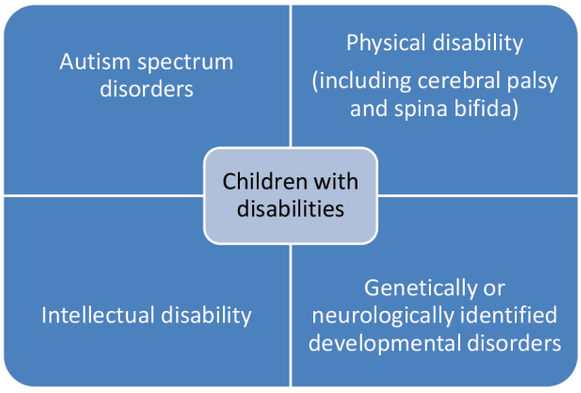
This report highlights achievements over the past two years and presents key current activities.

OUR HISTORY (CONT)

Neurodevelopmental differences

Disruption or differences in development of the brain or spinal cord can result in neurodevelopmental problems. When a neurodevelopmental disruption or difference causes problems with activities, function or participation it is called a neurodevelopmental disability. Other terms used to describe this type of problem include neurodevelopmental disorders, intellectual disability and developmental disability. Today we talk about broad categories of disability (Figure 2) such as those affecting social communication, known as autism spectrum disorders, those affecting physical ability, such as cerebral palsy and spina bifida, those affecting intelligence and those which are known to have genetic or neurological underpinnings that are often referred to by the genetic defect or syndrome name, for example Down Syndrome or Trisomy 21, or brain malformation, for example lissencephaly. Today more than 10% of males and 5% of females aged 5-14 years have a disability. More children are being diagnosed with an autism spectrum disorder than 10 years ago, and a similar number of children to previously are being diagnosed with cerebral palsy and other disabilities.

Figure 2. Different types of developmental disability

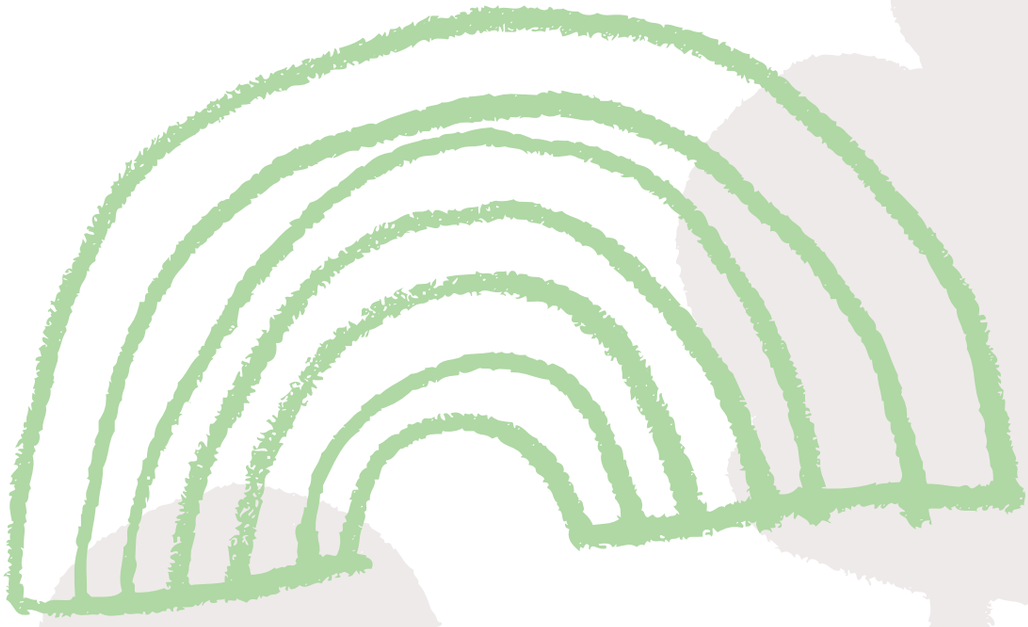


As technology advances, discoveries are being made that would not have been possible a decade ago. We can now conduct whole exome sequencing to assess genes relatively inexpensively, and we also have the ability to explore epigenetic (gene switching) differences. This means we are developing ways to understand the interactions between genes, early life environment (particularly during pregnancy) and neurological development. We are also working towards understanding how optimal brain development can be disrupted. In the not too distant future we are likely to have a new language for describing neurodevelopmental problems includes the specific type of genetic change in combination with the resulting neuroabnormality, whether that is structural, cellular or neurochemical in type.

While we make discoveries we must not lose sight of the individuals with neurodevelopmental problems. Evidence is still needed about how best to diagnose, intervene, provide information about the future and collect information that assists service development and policy. The International Classification of Functioning, Disability and Health provides the right approach for assessing the important interactions between impairments, function and participation and the many things that influence them.

The National Disability Insurance Scheme (NDIS) provides an opportunity to implement current best practice for diagnosis and intervention, and to be brave and compare interventions when best practice is unclear or debated, so that future generations of children with disabilities and their families can benefit. It also provides a framework to engage families as clinical and research partners, and to establish systems and activities for monitoring the interventions that are provided for children and their families to assess the outcomes of practices, service delivery and policy.

While we make discoveries and embrace changes to ensure we are always improving care, services and policy for children with neurodevelopmental disability we must also guard against falsely elevating hope, creating unrealistic expectations or promoting interventions that cause harm, for individuals, their family and the community. We also need to be ready to debate the benefits and risks of discovering the neurobiological underpinnings of ability and disability.



OUR SUPPORTERS (ADVISORY PANEL MEMBER)

PETER WATTS

Peter Watts has always been a contributor, a man who pitches in for the communal good. Growing up in the country, helping one's neighbour was a completely natural thing to do and throughout his youth pitching in to mow a neighbour's lawn or help on a nearby farm in a time of need was second nature. This has been a consistent theme throughout his life and after many years as a member of the Australian service club Apex, Peter accepted a role on the Board of the Apex Foundation for Research into Intellectual Disability (AFRID).

At the time, AFRID provided seed funding to multiple Australian organisations and researchers working in the field of developmental medicine. Peter first met Professor Dinah Reddihough AO through her role on the AFRID scientific sub-committee responsible for evaluating the proposals sent to Apex/AFRID for funding.

Peter was adamant about finding a way to make a game-changing contribution to improving the quality of life of children with disabilities and their families. "We really wanted to make a big splash in the pond, so I asked Dinah what we needed to do to create a breakthrough in developmental medicine," he says.

With Dinah's assistance, AFRID hosted a seminar at an international conference on intellectual disability to discuss with the conference guests and delegates how best to make use of AFRID's resources. Through this it became abundantly clear to the Board of AFRID that in order to make the impact they wanted, they should focus on the remarkable research opportunities in Australia and consider making one big contribution to support a significant project in perpetuity.

"The whole time Dinah had been assisting us by reviewing the many applications for AFRID's seed funding she had been almost silent about Solve@RCH," Peter says. "Such is her humility and professional ethics, she didn't want to prioritise her own interests, given her role with AFRID as Scientific Adviser. When we finally looked at Solve@RCH and the world-class research team they had, we realised that this was what we had been looking for."

In 2011 AFRID made the decision to fund The Apex Australia Chair of Developmental Medicine at the RCH. In 2014 AFRID proposed to give all of its accumulated funds to Solve@RCH – and in doing so dissolve AFRID – in order to endow in perpetuity The Apex Australia Chair of Developmental Medicine at the RCH, a position now occupied by Professor Katrina Williams, a leader in autism research and Head of Developmental Medicine at the RCH.

"We could have happily continued with our existing program of providing seed funding in smaller amounts to multiple projects but we had supreme confidence in Solve@RCH – we had seen the results they produced, we had seen the calibre of people on the Advisory Panel and how PhD students were lining up to be involved."

When the decision to fund the Chair in Developmental Medicine was made, Peter joined the Advisory Panel of Solve@RCH and stayed on as both a representative of AFRID as well as in his own right to contribute his expertise as a marketing consultant.

"I'm of the view that if you can make a splash in the pond, then let's do it. If you're as successful as Solve has been locally and internationally, then that attracts other success. Our contribution to that process raised the profile and other people jumped on board. It just needed someone to start it off and I am very proud to have been a part of that process."

OUR FAMILIES

COOPER SMITH AND BRON LEEKS

Cooper is an outgoing 10-year-old boy who loves to travel, fundraise and share his love of good food via his Instagram account The Wheel Foodie, which chronicles the food adventures of a 10-year-old who uses a wheelchair to explore.

Cooper also has cerebral palsy, which was diagnosed three days after he was born. As with many children with a developmental disability, Cooper's treatment is multi-disciplinary. He sees a physiotherapist once a week at school and an occupational therapist. Cooper also visits Professor Dinah Reddihough and Dr Adrienne Harvey from the Solve@RCH team twice yearly and has been involved in one of Adrienne's trials on treatment for dystonia.

Cooper and his family actively focus on the intrinsic rewards of an externally focused life together. Remarkably mature for his 10 years, Cooper quipped that "Christmas is about giving and being together as a family" when asked about his Christmas bounty when we met him for this interview. Indeed that attitude informs his approach to life – it is together that he and his family experience the world, embracing a life of travel and shared experience, and together they approach and overcome the hurdles of his cerebral palsy with a positive and deeply bonded shared purpose.

With assistance from occupational therapists and physiotherapists, the Smith family are committed to embracing and experiencing life to the fullest. To overcome poor accessibility issues in south-east Asia the family attach a third wheel to the front of their manual wheelchair so that Cooper can go up and down gutters when he is travelling.

When accessibility becomes too challenging, Cooper's mother Bron steps in to carry Cooper. On a recent holiday to Europe, Bron left the wheelchair at the door of Anne Frank's house in Amsterdam and carried Cooper through. He enjoyed the experience but joked: "Thank goodness Anne didn't have cerebral palsy because the stairs are so steep and the floors are cobblestone!"

This remarkable young man has some impressive achievements to his name. After researching Cambodia in preparation for a recent family holiday Cooper was moved by the poverty experienced by children there and set his mind to raising money for a Cambodian school. More recently in 2015 he raised more than $1000 with his two younger siblings in the Murdoch Childrens Research Institute Stepathon.

Describing the fun they shared at a recent disabled surfing event, Bron comments that she has recently detected a shift in their relationship as it matures from a parent's journey with a child who has cerebral palsy to that of a young person's journey growing up with cerebral palsy.

"Cooper now makes the decisions on what he would like to participate in," Bron says. "I often point out events for families and children with a disability, but it's up to him to choose to participate or not, and often he will choose mainstream events."

Maintaining his focus on maximising his participation in life, Cooper has big plans for the year ahead. He is reading up on Japan before a family holiday this year and planning this year's fundraising project.

OUR PEOPLE

DINAH REDDIHOUGH

For more than three decades paediatrician Professor Dinah Reddihough AO has been involved in the clinical care of children with disabilities, in particular cerebral palsy. As Director of Developmental Medicine at the RCH between 1986-2011 Dinah recognised an urgent need to raise the profile of research into childhood disability.

"Childhood disability used to be in the back room of hospitals, and in the back of people's minds," she says. "There was little or no research because childhood disability was seen as not 'curable' and therefore was not viewed as essential or urgent from a research perspective."

In 1987 Dinah founded the Victorian Cerebral Palsy Register, which is now one of the largest geographically-defined cerebral palsy registers in the world, holding information on more than 5200 individuals with cerebral palsy.

"As a clinician and researcher, I knew that a longitudinal record of information about every case of cerebral palsy in Victoria since 1970 would be a goldmine for focusing our research efforts and advancing our knowledge. By collecting this information we can, for example, identify trends in incidence, causes and risk factors, we can monitor the effectiveness of interventions and keep track of the changing needs of individuals with cerebral palsy as they age.

"Ultimately the goal of clinicians and researchers in developmental medicine is to significantly improve the quality of life of every child born with a disability, and the cerebral palsy register provides us with the information we need to provide better long-term help and support for children, their families and the communities in which they live."

Dinah's experience also highlighted the need for a critical mass of compelling research accompanied by a public advocacy body dedicated to childhood disability and developmental medicine.

Knowing the profound impact that small positive changes can have to the quality of life of a child with a disability, Dinah set her mind to creating the change that she wanted to see: specifically increased support and funding for childhood disability research and researchers.

"Childhood disability is not like an illness that can get better one day – it's lifelong. There is so much that can be done though, not only looking at the causes of disability but also improving quality of life for those with a disability."

In 2004 she gathered a group of influential, committed and aware individuals from the Murdoch Childrens Research Institute, the RCH, its Foundation and auxiliaries, the University of Melbourne, parents of children with a disability and community representatives. This became the Advisory Panel of Solve@RCH, chaired by the esteemed economist and, more recently, pioneer of the National Disability Insurance Scheme Bruce Bonyhady AM.

In her trademark, understated manner, Dinah speaks proudly of the collegiate effort to raise the profile of research in developmental disability since the official launch of Solve@RCH in 2006.

"We could not have achieved any of this in isolation: researchers couldn't have done without the encouragement and support provided by the Solve Advisory Panel, the auxiliaries and the RCH, MCRI and the RCH Foundation. Coming together has enabled us to do much more than we could have done on our own.

"The success of Solve comes back to the impressive skill-sets of both the Advisory Panel members and researchers. We have set up a system that optimises the potential for research break-throughs in developmental medicine. The area of impact is up to the researchers' discretion based on their experience of the children and families they see, while the Advisory Panel of Solve provides guidance and a structure for fundraising and public support.

"The local and international impact of the generosity of the Apex Foundation, and more recently philanthropist Pamela Galli, in creating our two chairs of developmental medicine cannot be overstated. Their generosity and foresight has allowed paediatricians and researchers to expand their programs, initiate pilot studies and build powerful impetus behind research in this area to support other funding applications."

While much has been achieved in 10 years by Solve@RCH, Dinah emphasises that there is still a long way to go: "We work for small changes. The things that keep me going are the families and children I work with. While often coping with severe disabilities and setbacks, they are without fail resilient, optimistic and often very brave. They are why we stay committed."

ADRIENNE HARVEY

Dr Adrienne Harvey's transformative research into dystonia in children with cerebral palsy is supported by Solve@RCH. Adrienne trained as a physiotherapist and is working as a clinical researcher in Developmental Medicine at the RCH. In 2015 she was awarded a Melbourne Children's Campus Career Development Award, which allows her to focus on her research into dystonia alongside her role in Developmental Medicine.

Dystonia is a movement disorder characterised by involuntary muscle contractions that can cause the child pain and distress and interfere with their function and quality of life.

"It's a movement disorder that we have really only recognised accurately in the last 10 years," Adrienne says. "In the past involuntary muscle spasms were often classified as a type of spasticity, but only recently have we realised that dystonia behaves quite differently: it is harder to identify and manage effectively and can get worse as the children grow."

Detecting and measuring dystonia in children with cerebral palsy has improved over the past 10 years but no breakthroughs have been made in treatment.

Adrienne explains: "The oral medications that are currently available often have nasty side-effects, or their effectiveness varies. Research into treatment is particularly challenging because each child presents differently and will have varying associated problems, so they will respond differently to the range of drugs available."

For these reasons there is still a critical gap in the research on treating dystonia. Trials are particularly difficult to conduct in this population and evidence about the usefulness of drugs is scarce.

"The children and their families are fantastic to work with and are always happy to participate in research, but it can be hard to attract funding for this type of research," Adrienne says. "Solve@RCH helps us to drive this really important research agenda and coordinate our quest to secure funding for it."

Adrienne's current research is focused on ensuring consistent measurement of dystonia, using validated tools to assess not only the involuntary muscle movements but also their impact on the child's function and quality of life. She is also investigating the effectiveness of the currently available medications used by doctors to treat dystonia in children with cerebral palsy.

"Solve@RCH is not only a body that drives fundraising efforts to support ongoing research, but it also acts as an advisory group of established practitioners and individuals from a range of different backgrounds that can evaluate and direct the research once funding is secured.

"The multi-disciplinary reach of Solve@RCH is integral to successfully tackling issues that require a multi-disciplinary response. Some of my research is around medications and their effects and side-effects. This is obviously not traditionally a typical physiotherapy topic. However I work with the pharmacists and doctors who have the necessary medication expertise and my skills are in designing the studies, measuring the outcomes and overseeing the research process. In the field of disability research it's very much a team approach and you have to approach questions collaboratively for best results."

For the next three years Adrienne will continue her research in dystonia as part of the NHMRC Centre of Research Excellence in Cerebral Palsy grant, collaborating with researchers in Australia and internationally.

"What inspires me to keep going is seeing the children benefit and improve from our management and seeing them participate fully in everyday life. We can't cure cerebral palsy but we can certainly help to make the lives of children and their families as enjoyable as possible. For me, what I love seeing is kids and their loved ones able to do what they want to do as a family and as individuals."

RESEARCH RESOURCES

THE VICTORIAN CEREBRAL PALSY REGISTER (VCPR)

Cerebral palsy is the umbrella term used to describe children who have ongoing problems with their movements and/or posture as a consequence of disturbance to the brain before, during or soon after birth. The movement problem limits the ability to perform activities of daily living and may be accompanied by additional disorders and impairments such as epilepsy, sensory impairments, intellectual disability, communication difficulties and secondary muscle and joint problems.

The VCPR is the cornerstone for much of the cerebral palsy research performed in Victoria. It is an invaluable resource for describing trends in prevalence, health service use, survival and clinical characteristics of individuals with cerebral palsy in the Victorian population, and facilitates important research investigating the causes of cerebral palsy and strategies for achieving the best outcomes for individuals with cerebral palsy and their families.

At the end of 2015 there were 5367 individuals born after 1970 who were registered on the VCPR, representing more than 100 new diagnoses per year. Over nearly 30 years, the VCPR has been involved in 83 separate research projects, as a result of which 91 papers have been published in peer-reviewed journals. The VCPR also continues to contribute Victorian data to the Australian Cerebral Palsy Register, which is due to publish its next report in 2016.

VICTORIAN PRADER-WILLI SYNDROME REGISTER (VPWSR)

First described in 1956, Prader-Willi syndrome is the result of a genetic defect affecting imprinted genes on chromosome 15 at q11–13. The syndrome is characterised by floppiness and failure to thrive in the newborn period, intellectual disability, specific behavioural problems, excessive or rapid weight gain during childhood and increased appetite that often leads to obesity. The VPWSR is an ideal research platform for answering questions that are important to clinicians and researchers, as well as to individuals with PWS and their families. Its aims include improving our understanding of the incidence, morbidity and mortality of Prader-Willi Syndrome.

The VPWSR collects and stores information about individuals with Prader-Willi syndrome who were born, living and/or receiving services in Victoria. At the end of 2015, there were 202 individuals known to the VPWSR, with ages ranging from 0-65 years. To date, the results of two population-based studies have been published and presented internationally, and two additional publications have used VPWSR data. More than one-third of families have consented to receive three-yearly questionnaires, to allow an understanding of how health and wellbeing change over time. There is growing interest from researchers and parents in the VPWSR as a means of facilitating research and also in the development of a national Prader-Willi syndrome database.

VICTORIAN NEURAL TUBE DEFECTS REGISTER (VNTDR)

Neural tube defects (NTDs) are caused by incomplete formation of the spinal cord and overlying tissues during the first 28 days of pregnancy. A related birth defect, sacral agenesis (absence or malformation in the development of the sacrum or caudal portion of the spine), has neuropathic sequelae that overlap significantly with the commonest NTD. Spina bifida occulta does not cause neurological impairments and is not included in the register.

The severity of NTDs and the effect they have on each child varies widely. Most children have muscle weakness impairing mobility, bladder and bowel abnormalities impairing continence, and learning difficulties, particularly those associated with organisation and memory. All of these are likely to

affect the level of independence and self-care.

The complexity of these conditions means that the health care of a child (and adult) with a NTD or sacral agenesis requires a multidisciplinary team of specialists, including paediatricians, urologists, neurosurgeons, orthopaedic surgeons, continence nurses, orthotists, physiotherapists, occupational therapists, psychologists and social workers.

The aim of this project is to establish a registry of children attending the RCH service that will allow us to better understand the medical, educational and social needs of this population. It is envisioned that the VNTDR will be expanded at a later stage to become a state-wide registry for children and adults, collaborating with our Monash Medical Centre colleagues. Three levels of participation are possible:

1) ascertainment to capture prevalence and type of lesion;
2) gathering of clinical information for the duration of care of the child at RCH; and
3) consent for invitation to join future relevant ethics-approved research.

One hundred and eighty children and young people who have attended the RCH in the past 10 years have been ascertained. To date, 58 families have been informed about the VNTDR and data entry is now complete for nearly half of them (26).

Through the register we will be able to improve our understanding of risk and protective factors for outcomes and initiate studies of interventions. This will aid the development of guidelines to improve clinical care and health, participation and wellbeing.

THE MELTON DEVELOPMENTAL DIFFERENCES DATABASE (M3D)

Developmental differences create concern for parents and often result in them seeking advice. If a difference persists then multidisciplinary assessment is needed to identify important diagnoses and to better understand strengths and difficulties, so that additional support can be provided as needed. Despite many advances in our understanding of neurodevelopment, much is still not known about the occurrence of types of developmental differences, their associations and their outcomes.

M3D is an initiative from collaborative partners across Djerriwarrh Health Services, The Royal Children's Hospital, the University of Melbourne and the Murdoch Childrens Research Institute. This collaboration was established in recent years when team members identified the need for a comprehensive database that can support current and future research activities and inform clinical practice for developmental differences and disability.

The aim of the M3D is to provide a population-based research platform that can help researchers investigate prevalence, characteristics, potential causes and developmental pathways of children with developmental differences and disabilities living in the Melton region of Victoria. The M3D will house information relating to children and families who have had a developmental assessment completed by the Autism Spectrum Assessment Clinic and the Developmental Assessment Clinic at Djerriwarrh Health Services. Ethical approval was obtained for M3D in 2015, and work has begun to establish a core dataset and provide information about the development of M3D to eligible participants. The database will be managed by the Autism Research Team, and will be housed at the Murdoch Childrens Research Institute.

It is anticipated that in 2016 data relating to more than 200 children with varying developmental differences will be included in M3D. To our knowledge, no such database exists in a region where families of children with developmental difficulties typically access a single, unified assessment service. As such, M3D provides a unique opportunity to track an entire population of children with developmental differences within a defined geographical area.

CENTRE FOR RESEARCH EXCELLENCE IN CEREBRAL PALSY (CRE-CP)

The CRE-CP is a five-year, NHMRC-funded project that brings together leading researchers, clinicians and consumers from across Australia and the globe. The CRE-CP aims to improve the physical, mental, social and emotional health and wellbeing of children with cerebral palsy and their families. Now in its third year, the CRE-CP continues to work closely with researchers, clinicians and families in an effort to bring about change in the management and treatment of cerebral palsy.

The CRE-CP team consists of a collaborative group of clinicians, researchers, students and families that all work together to achieve the CRE-CP's aims. Partners include the Murdoch Childrens Research Institute, the RCH, the University of Melbourne, Australian Catholic University, the Cerebral Palsy Alliance, Deakin University, the University of Sydney, the Telethon Kids Institute and Western Australia's Department of Health.

Over five years, the multi-faceted research program will include a range of clinical trials, systematic reviews and training opportunities, leading to the implementation of evidence-based care.

Figure 3. Research streams of the CRE-CP

Allied Health

RCT: Do rigid upper limb orthoses prevent or reduce the development of hand and wrist contracture?

Studies evaluating the effectiveness of common treatments for saliva control problems

Implementation of a formal, state-wide hip surveillance program for children with cerebral palsy

Bike riding ability in children with cerebral palsy compared to typically developing peers

Medical & Surgical Interventions

A research program on managing dyskinesia in children with cerebral palsy

RCT evaluating soft tissue surgery versus bony surgery in the management of displaced hips

Mental Health & Participation

Development of a new quality of life measurement tools; for children and for parents and carers

Improve outcomes and support available for mothers of children with disability

A research program designed to help young adults achieve their personal and community aspirations

Research Projects

The many studies under way are shown in Figure 3. Our two clinical trials are actively recruiting children, one on upper-limb orthoses and the other on surgical management of displaced hips. An advisory committee of clinicians, researchers and parents has been established to lead the dyskinesia research program, and the hip surveillance project is progressing (see details page 19). We have appointed five PhD students, studying at the University of Melbourne, Deakin University, and the Australian Catholic University, who are working on projects in quality of life; creating new measurements, updating existing tools and evaluating measures used in health economics related to disability; and saliva control.

Education and Events

One of the main aims of the CRE-CP is to provide an education program through seminars, fact-sheets, publications, podcasts and videos in a format that families and health professionals can access. There have been two key events over the past 24 months.

The first, called Pathways to Possibilities, was the inaugural symposium of the CRE-CP, held in Melbourne on 4 May and in Perth on 8 May 2015. Professor Darcy Fehlings from Bloorview Children's Hospital in Canada and local speakers delivered a program centred on evidence-based best practice that will ultimately improve the health and wellbeing of children with cerebral palsy and their families. Feedback included quotes such as this one: "Fantastic event and learnt some very valuable information regarding dystonia that will assist me in the clinical setting. Felt very privileged to listen to such knowledgeable speakers."

The second was the first CP FACTS seminar, a free half-day family event designed to provide information related to cerebral palsy through presentations and exhibits, with time for questions and one-on-one conversations. Children of participant parents were supervised by volunteers and participated in a range of games and activities. The seminar was a great success, with feedback including "I was very impressed with the structure and content of the session. It was totally relevant to our situation. It was amazing to get information in a 'one stop shop'!". It is planned to hold CP FACTS annually.

Summary

The CRE-CP team looks forward to continuing the success of the past two years and has plans in place for a number of initiatives which will contribute to increasing knowledge in the field and developing the next generation of researchers and clinicians. These include a leadership program for researchers, a number of knowledge transfer fellowships to facilitate the application of evidence-based knowledge, and increased support of PhD students through a country-wide top-up scholarship scheme. Exciting things to look forward to!

RESEARCH TOPICS

PREVALENCE

CEREBRAL PALSY

Temporal trends in the prevalence and severity of cerebral palsy not only afford insight into changing clinical and health service delivery needs but are also valuable markers for monitoring the impact of innovations in perinatal practice and the effectiveness of treatments aimed at protecting the brains of newborn infants. In a study using data from the Victorian Cerebral Palsy Register for birth years 1983-2009, researchers from Developmental Disability and Rehabilitation Research assessed trends in the rates of cerebral palsy of different levels of severity within birth gestation groups. They established that the rate of cerebral palsy in infants born at all birth gestations rose throughout the 1980s and early 1990s but declined through the latter half of the 1990s and 2000s. The data suggested relatively greater declines in cerebral palsy rates over the study period for the more severely affected and/or complex subgroups. These declines in the rates of cerebral palsy of all levels of severity and complexity from the mid-1990s provide support for the effectiveness of continual innovation in perinatal practices. A further study exploring the effects of gender on cerebral palsy prevalence found that the temporal changes were gender-dependent. Preterm males showed more dramatic changes over time in cerebral palsy rates than preterm females, but we observed little change in the overall male:female ratio.

Two recent publications and five international and national presentations have resulted from this research.

AUTISM SPECTRUM DISORDER

Using population-based data from the Longitudinal Study of Australian Children, the Autism Research Team published an important paper in the Australian and New Zealand Journal of Psychiatry which reported an increased prevalence of autism spectrum disorder in Australia. The research found 2.5% of children under 7 years of age had an autism spectrum disorder diagnosis, an increase from 1.5% found four years earlier in the older cohort. This research was able to utilise the two-cohort design of the study to comment on possible associations with government funding that was available for children with autism in the younger but not the older cohort. This work will be continued within the team in the coming year to further explore the prevalence as well as causes of autism using later waves of data.

CAUSE

WHAT CAN WE LEARN FROM TWINS?

It is possible that epigenetics could play a role in neurodevelopmental differences, including the development of cerebral palsy and autism spectrum disorders. Epigenes control gene activity and their action can be influenced by the environment.

Although cerebral palsy may originate before birth, diagnosis is often delayed. We propose that "epigenetic" gene switches known to be influenced by the environment in the womb or during the first few days of life have the potential to be used to identify which babies will develop cerebral palsy. Early identification would pave the way for immediate interventions that might ameliorate the symptoms of this condition. We are studying a group of identical twin pairs, each of which is discordant for cerebral palsy, to help us focus on differences within twin pairs in their early environmental experiences rather than on genetics, since the identical twins are genetically the same. We have analysed dried blood samples taken at birth and are continuing to explore ways to take this research to the next level.

Autism spectrum disorder is a complex developmental disorder characterised by social communication

problems and restricted, repetitive patterns of behaviour. There is still much to be learnt about mechanisms that are on the causal pathway to autism spectrum disorder. Twin studies that control for variability associated with genes and shared environments are particularly valuable in examining factors that may be important in disorder development. In the UNIQUE Autism research project, we are examining similarities and differences between identical twins where one or both children have autism spectrum disorder. We are looking at both behaviour and genetics, with a particular interest in "epigenetic" gene switches. The detailed examination of behaviour, cognition and functioning of each child, coupled with the epigenetic analysis, makes this study unique. We have had five sets of twin pairs participate to date, and are finding that even when both twins have a diagnosis of autism spectrum disorder, their thinking skills, behaviour and functioning are often different in important ways. In the future, we will be seeking funding to expand the study to include sequencing of all the DNA ("whole genome sequencing") for each pair of identical twins to check for genetic differences, as a small number of recent studies have found that even "identical" twins sometimes have differences in their DNA code. Such differences could work together with the epigenetic differences to contribute to the development of autism spectrum disorder.

WHAT ARE WE LEARNING FROM MAGNETIC RESONANCE IMAGING FINDINGS?

For many families, the cause of their child's cerebral palsy is not well understood. With improvements in brain imaging, however, more is known about the type of brain injury that has occurred, even if the reasons for the initial injury remain unrecognised, especially in children who have no symptoms in the newborn period. A program of research is being undertaken within the Developmental Disability and Rehabilitation Research group to classify the main patterns of brain injury seen in children with cerebral palsy and to better understand how the patterns of injury relate to clinical profiles. Using this knowledge and data held on the Victorian Cerebral Palsy Register, we are exploring causal pathways to cerebral palsy within groups of children who have similar types of brain injuries. Mothers have been invited to participate in this study by completing a questionnaire about their health and pregnancy and the birth and early life of their child. This research has resulted in five publications over the past two years, and more papers are in preparation.

IDENTIFICATION AND DIAGNOSIS

HIP SURVEILLANCE

The CRE-CP hip surveillance project aims to develop and implement a framework for hip surveillance for all Victorian children with cerebral palsy that is efficient, sustainable and well accepted by both families and health professionals. The first step has been to explore the current barriers to effective hip surveillance with two studies. A survey of Victorian health professionals was conducted to assess the current state of practice of hip surveillance and to explore the barriers and facilitators encountered by health professionals in implementing routine hip surveillance. Results of this survey are being analysed. The second study involves parents and carers of children with cerebral palsy participating in group discussions to explore parent perspectives of hip surveillance. These focus groups are continuing.

In addition, the team has developed a knowledge translation and stakeholder engagement plan, consulted with service providers regarding a technological framework for implementation of the hip surveillance program and disseminated current research and best practice through presentations to key stakeholder groups.

PAEDIATRIC PRACTICES WHEN DIAGNOSING AUTISM SPECTRUM DISORDERS

A multi-topic survey was used to explore autism diagnostic practices of paediatricians. This study highlighted a lack of consistency of practice in Australia and found that diagnostic processes often fall short of recommended practice. While most paediatricians spent considerable time making a diagnosis of autism spectrum disorder and used recognised classification systems, they did not always have relevant assessment information available at the time of diagnosis, such as cognitive, developmental and speech pathology assessments. Genetic and audiology assessments were also not always ordered. There were a number of reasons given by paediatricians as to why tests were not ordered, including out-of-pocket costs for assessment, lack of local services and long waiting lists. Such barriers will need to be addressed to optimise accurate diagnoses, identify children's strengths and to plan the best possible services for all children. This work was published in January 2016.

PROGNOSIS

LONGITUDINAL FOLLOW-UP OF CHILDREN WITH AUTISM SPECTRUM DISORDER AGED 10 AND 15

While the clinical features of autism spectrum disorder have been continually investigated since the term was first described in the early 1900s, relatively little is known about the prognosis and long-term outcomes. In 2015, ethical approval was obtained to investigate clinical features and levels of functioning in young people aged 10 and 15, where a previous diagnosis of autism spectrum disorder had been made before or at the time of school entry. In particular, language abilities, cognition and symptom severity will be explored and compared to participants' characteristics at the time of diagnosis. Funding from the Perpetual Trust and the RCH Foundation is supporting the recruitment and assessment of participants, underway since late 2015.

INTERVENTION STUDIES

MENTAL HEALTH CARE FOR MOTHERS OF CHILDREN WITH A DISABILITY

Interviews and surveys have been held with mothers and health professionals to ask about their experiences with mental health, and what change they would like to see in health and disability services. This will provide much-needed information about what changes are required to make mental health care more accessible to mothers who most need support, and what systems of prevention and early detection of poor mental health can be implemented, with the aim of reducing the number of mothers who experience poor mental health outcomes.

'FAB TRIAL' - FLUOXETINE FOR THE TREATMENT OF AUTISTIC BEHAVIOURS

Over the past decade, the use of fluoxetine and other selective serotonin reuptake inhibitors (SSRIs) for treating children and adolescents with autism spectrum disorder has increased, but the safety and effectiveness of their use is still unknown. This randomised controlled study aims to assess:

1) the safety and effectiveness of fluoxetine, for reducing the frequency and severity of repetitive behaviours in children and adolescents with autism spectrum disorder; and

2) whether a relationship exists between an individual's serotonin transporter genotype and response to treatment with fluoxetine.

To date, 143 participants have been recruited; 122 have been randomised to receive fluoxetine medication or placebo, 33 participants have withdrawn and 18 are currently in the trial. The study runs across three sites: the RCH, Victoria, the Children's Hospital at Westmead, New South Wales and the State Child Development Centre, Western Australia. Findings from this trial will be incorporated into guidance about appropriate use of fluoxetine for children with autism spectrum disorder.

STEM CELLS

Stem cells have provoked considerable interest as a potential therapy for cerebral palsy but research regarding the safety and effectiveness of these cells is very limited. An Australian collaboration has been established to undertake research in this area, headed up by our research team. Following a long period of deliberation as to the best way forward, a small pilot study involving 12 children aged between one and 12 years began in February 2016. The main purpose of this study will be to evaluate the safety of sibling stem cell transfusion. Families with a child with cerebral palsy and sibling stored cord blood cells will be invited to participate. The children will receive detailed clinical assessments both before and after the infusion. If the procedure is found to be safe, then this pilot research will form the basis for a larger study to assess effectiveness in improving movement, function and participation.

HIGHLIGHTING CURRENT PHD PROJECTS CO-SUPERVISED BY OUR STAFF *(enrolled for some or all of 2014-2015)*

Amanda Brignell
(Language trajectories and outcomes in autism spectrum disorders)

Amanda is studying trajectories of communication development and predictors of communication outcomes in children with autism spectrum disorder. She is completing a systematic review of language outcomes in autism spectrum disorder and using data from a large population-based longitudinal study: the Early Language in Victoria Study.

Elaine Meehan
(Health service use by children and young people with cerebral palsy)

Elaine's PhD is investigating the use of medical services among children and young people with cerebral palsy using data linkage techniques. Specifically, she is investigating the patterns of use of hospital emergency department and inpatient services in children and young people with cerebral palsy by linking the Victorian Cerebral Palsy Registry to state-wide health service datasets. The availability of population-based data on medical service use in this population is important given that cerebral palsy is the most common cause of physical disability in children, and the need for medical care in this group remains high throughout childhood and adolescence and into adulthood. A better understanding of how medical services are used will provide an objective basis for service planning.

Francesca Lami
(The relationship between neuropsychological function and participation in ASD)

Autism spectrum disorder is a developmental disorder characterised by impairment in socio-communication and presence of repetitive behaviours and restricted interests, to an extent that these significantly impact everyday functioning. Francesca's PhD will explore factors associated with better participation and quality of life in cognitively able adolescents with autism spectrum disorder. To understand this relationship, she will be look at the relationship between neuropsychological functioning, autism spectrum disorder domain-related behaviours, social participation and adaptive functioning.

Monica Cooper
(Epilepsies in children with cerebral palsy)

Monica is exploring the frequencies, types and evolution of epilepsies in children with cerebral palsy and white-matter injury (born between 1999 and 2006). The neuroimages, patient histories and electroencephalograms (EEGs) will be reviewed. This has implications for treatment options for epilepsy associated with cerebral palsy, both type of drug and length of treatment, and counselling. Monica will also review information about children born between 1999 and 2006 with cerebral palsy (with white-matter injury/grey-matter injury/stroke) who have had infantile spasms, to assess their outcomes at follow-up and to identify risk factors for this group.

Rachel Toovey
(Motor learning in children with cerebral palsy)

Rachel is exploring motor learning in children with cerebral palsy with a focus on the skill of learning to ride a two-wheel bike. Bike-riding is a common childhood milestone, yet a lower proportion of children with cerebral palsy who can walk independently are able to ride a bike independently, compared to their typically developing peers. Rachel's PhD will examine the current evidence base for motor learning approaches and apply these findings to an intervention study exploring the effects of bike-skills programs in this population.

Rebecca Mitchell
(Developmental outcomes of tuberous sclerosis complex)

Rebecca is investigating autism spectrum disorder in children with a genetic condition called tuberous sclerosis complex. The major aims are to uncover neurobiological pathways that lead to the high rates of autism spectrum disorder and other neurodevelopmental problems in this group of children and to better understand the "type" of autism spectrum disorder they have. This will enable clinicians to better target medical treatments to improve developmental outcomes and promote better developmental care for these children. It is also hoped that insights will be gained into the underlying causes of autism spectrum disorder more generally.

Susan Woolfenden
(Developmental vulnerability and its underpinnings)

Susan investigated inequities in the prevalence of developmental vulnerability, associated risk factors and their interactions, and explored factors that influence access to early identification and intervention. She found inequities in developmental vulnerabilities driven by differential risk, knowledge, quality and access that all need to be addressed if risk of developmental vulnerability is to be minimised and inequities overcome. PhD submitted in 2015, currently being examined.

Neda Taghizadeh
(Anaesthetic preparation for children with autism spectrum disorder)

Neda is exploring the experiences of families with a child with an autism spectrum disorder when they attend for a procedure under general anaesthesia, existing evidence about best practice for preoperative care and developing a trial of premedication to assess which approaches and agents are most effective.

Sacha Petersen
(Bedtime stories: An exploratory study of sleep disturbance for children with cerebral palsy and their parents)

Children with cerebral palsy (CP) and their parents commonly report poor sleep. The primary aim of this PhD study is to understand the reasons for and the impact of sleep disturbance for children with CP and their parents. The information generated by this study may inform a future evidence-based intervention to address sleep issues for children with CP. This project, through a consumer informed understanding of sleep issues, will address a significant gap in evidence; there are no published studies exploring an intervention of this kind. The research hypothesis is that some of the sleep disturbance experienced by children with CP may be caused by treatable care and comfort factors associated with the comorbidities of cerebral palsy.

TRAINING AND EDUCATION

We provide disability-focused education and training to doctors, nurses, allied health and education professionals and parents/carers of children and young people living with disability. Over the past two years we have continued to run a series of face-to-face training events. In 2014-15 we also began online learning. A series of webinars were held for parents and carers which were accessed in a range of places, with positive feedback. An online education program for health and education professionals followed. Online events have been recorded, allowing us to build an online library of learning resources.

Training for health and education professionals has included:

- Two full-day seminars for health and education professionals:
    - Autism Spectrum Disorder: Managing Challenging Behaviours, June 2014, and
    - Behaviour Management in Children & Young People with Dual Disability: A strategy-based approach, June 2015;
- One half-day symposium for paediatricians and health professionals:
    - Cerebral Palsy – A Changing Landscape. Diagnosis and Management in 2015 and Beyond, August 2015 with keynote speaker Professor Peter Rosenbaum, McMaster University, Canada;
- Four webinars on disability-focused topics;
- More than 116 different presentations (both local and international) resulting in more than 130 hours of training to various programs and groups; and
- Orientation and supervision for trainee medical staff working at the RCH.

For parents/carers five webinars were offered, designed to provide relevant, evidence-based information that would inform their decision-making.

Since utilising e-learning we have experienced a 700% increase in uptake of training.

To improve our communication and create a content management system for our growing library of resources we have also developed a new, purpose-built website. Thanks to all the families, children and young people who agreed to be photographed. We hope our new website provides clear information about our vision, mission and goals, as well as focused information for families who have developmental concerns about their child. The website has a rolling blog of our latest news and events and the facility to register for and purchase training (for professionals). In the first three months since the launch of the website, traffic to the home page has increased by 50% and traffic to the education and training page has increased by 80%. Those interested can also subscribe to our monthly e-newsletters. We have more than 1000 subscribers on our mailing list now and our emails have been opened in more than 25 countries.

FUTURE ENDEAVOURS

Encouraged by the positive feedback we will continue webinar-based training events and will trial information-sharing podcasts. Both will be used to build our library of online resources. Our face-to-face events will continue, with the half-day symposium scheduled to become an annual event.

TABLE 1

COMPETITIVE RESEARCH FUNDING 2014 AND MORE RECENT

YEAR	FUNDING AGENCY	INVESTIGATORS	TOPIC	AMOUNT
2016-2018	ARC Discovery Grant	Goldfeld S, Williams K, Redmond G, Oberklaid F, Badland H, Freed G, Mensah F, Woolfenden S, Proimos J, Kvalsvig A, Ahmed E	Changing children's chances: Exploring pathways to developmental inequities.	$760,000
2016-2020	ARC Project Grant	Rinehart R, Sciberrs E, Hiscock H, Williams K, McGillivray J, Howlin P, Papadopoulos N.	Tailoring a brief sleep intervention for autism: a randomized control trial.	$401,474
2016-2018	NHMRC Project Grant	Downs J, Leonard H, Williams K, Davis E, Reddihough D, Whitehouse A, Jacoby P	Characterising quality of life and its determinants for children with intellectual disability and their families.	$520,874
2015-2018	Melbourne Children's Campus Career Development Award	Harvey A	Towards evidence based management of dystonic cerebral palsy: a model for all children with neurodisability	$120,669
2015-2016	The Perpetual Trustees Foundation	Williams K., Randall M., Brignell A.	Follow up study of children aged 10 and 15 years with Autism Spectrum Disorders.	$33,928
2015-2016	Jack Brockoff Foundation	Williams, K., Craig J	Understanding similarities and differences between twins	$66,230
2015	Clinical Sciences Theme grant, Murdoch Childrens Research Institute	Harvey A, Scheinberg A, Williams K, Reddihough D	A pilot study of gabapentin for managing pain in children with dystonic cerebral palsy	$10,000
2014-2018	National Health and Medical Research Council Partnership Project APP1076861	Waters E, Davis E, Chan J, Reddihough D, Carter R, Williams K, Gibbs L, Reynolds J, Tracy J & McDonald R.	Developing and evaluating a new cost-effective health and wellbeing model of care for disability service providers	$578,308
2014-2018	National Health and Medical Research Council APP 1057997	Reddihough D, Graham HK, Imms C, Badawi N, Waters E, Blair E, Carter R	A Centre for Research Excellence in Cerebral Palsy	$2,500,000
2014-2018	National Health & Medical Research Council. Early Career Fellowship	Reid S	Improving our understanding of the causes of cerebral palsy	$304,596
2014-2016	National Health & Medical Research Council. Project Grant	Reid S, Dagia C, Reddihough D, Ditchfield M, Carlin J, Blair E, Cheong J.	Understanding white matter injury in term-born children with cerebral palsy	$188,642
2014-2016	The Scobie & Claire Mackinnon Trust	Muscara F., Harford R., Anderson V., O'Neill J	Treating parents' distress following their child's diagnosis of cerebral palsy: A pilot study	$54,851
2014-2016	Australian Catholic University Research Fund	Imms C, Reddihough D, Hoare B, Wallen M, Elliot C, Greaves S, Randall M, Bradshaw E, Adair B	Minimising impairment: A multicentre randomised controlled trial of upper limb splinting for children with cerebral palsy	$775,000
2014-2015	The Hugh D. T. Williamson Trust, ANZ Foundation.	Williams K., Craig J	UNIQUE Autism: Understanding similarities and differences between twins	$29,844
2014	Clinical Sciences Theme grant, Murdoch Childrens Research Institute	Williams K, Craig J, Randall M.	A twins epigenetic approach to causes of autism spectrum disorder	$15,000
2012-2015	National Health & Medical Research Council Partnership Project Grant APP 1055278	Imms C, Novak I, Reddihough D Graham HK, Shields N, Coory M	The best service at the best time: Improving the implementation of research for children with cerebral palsy.	$865,853
2011-2015	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
Total				**$7,573,715**

STAFF

Employer	Discipline	Staff member	EFT
RCH	Medical	Professor Katrina Williams1	1.0
	Medical	Dr Enver B*	0.2
	Medical	Dr Catherine Marraffa	0.4
	Medical	Professor Dinah Reddihough1	1.0
	Medical	Dr Margaret Rowell	0.2
	Medical	Dr Giuliana Antolovich	0.6
	Medical	Dr Kate Thomson-Bowe	0.7
	Medical	Dr Louise Baker2	1.0
	Medical	Dr Kate Milner	0.5
	Medical	Dr Susie Gibb	0.5
	Medical	Dr Biola Araba (2014)	0.5
	Medical	Dr Katherine Wilkins (2014)	0.5
	Medical	Dr Sid Vemuri (2015)	1.0
	Psychology	Ms Margaret Charlton	0.3
	Nursing	Ms Marijke Mitchell	0.6
	Nursing	Ms Sacha Peterson	0.4
	Nursing	Ms Jenny O'Neill	0.6
	Nursing	Ms Judy Wells	0.8
	Nursing	Ms Carmen Akoui	0.6
	Nursing	Ms Sarah Ziegerink	0.6
	PT	Dr Adrienne Harvey3	0.4
	OT	Dr Melinda Randall4	0.4
	OT	Ms Charmaine Bernie (2015)	0.6
	PT	Ms Melanie Toy-Laing (2015)	0.4
	Administration	Ms Elizabeth Cassidy	1.0
	Administration	Ms Caroline Pobega (2015)	0.6

1. UoM and RCH
2. Works 0.2EFT with the VPRS
3. Also works 0.4EFT with MCRI
4. Also worked 0.6 EFT with UoM until May 2014

*retired or moved to other work
PT Physiotherapist OT Occupational Therapist
SP Speech Pathologist
EFT Equivalent Full Time
(PhD) also a PhD student
UBCDC Uncle Bob's Child Development Centre

Employer	Discipline	Staff member	EFT
UBCDC	PT	Ms Michèle Spreckley (Manager)	1.0
	Coordinator	Halina Campbell	0.7
	Coordinator	Suzy Marty	0.6
	SP	Trudy van Meggelen	1.0
	Administration	Marilyn Brady*	0.2
	Administration	Annie Zhang (2015)	0.4
	Psychologist	Dr Jessica Mifsud	1.0
	SP	Erica Casey	1.0
	SP	Erin Bainbridge	0.4
	OT	Rhiannon Memery	1.0
	OT	Adele Rullo	1.0
	OT	Liat Sifris	1.0
	SP	Laura Doig (2015)*	1.0
	SP	Oi Yi Pun (2015)*	0.4
	Kinder assist	Tina Milesi (2015)	0.4
	Facilitator	Maria Rasquinha	casual
	Facilitator	Joanne Madaffari	casual
MCRI Developmental Disability & Rehabilitation Research Group	Research	Dr Sue Reid	1.0
	Research	Ms Molly O'Sullivan	0.2
	Research	Ms Christine Westbury	0.4
	Research	Ms Elaine Meehan (PhD)	0.4
	Research	Dr Kylie Crompton	0.6
	Research	Ms Kate Willoughby	0.6
	Research	Ms Rachel Toovey (PhD student)	?
	Research	Ms Angela Guzys (2014)	
	Research	Ms Tess Lionti*	
	Administration	Ms Tessa Devries	0.8
	Administration	Ms Debbie Cations (2015)	0.2
UoM	Psychology	Ms Felicity Klopper	0.4
	SP	Ms Amanda Brignell (PhD)	0.2
	Psychology	Mr Shawn Stephenson	1.0
	Psychology	Dr Tamara May (2015)	1.0
	Science	Dr Kristine Egberts (2015)	1.0
	Administration	Ms Michelle Nelthropp *	1.0

PUBLICATIONS PAST 5 YEARS

2015

1. Crick K, Wingert A, Williams K, Fernandes R, Thomson D, Hartling L. An evaluation of harvest plots to display results of meta-analyses in overviews of reviews: A cross-sectional study. BMC Medical Research Methodology. 2015; 15(1). IF: 2.27

2. Epstein A, Leonard H, Davis E, Williams K, Reddihough D, Murphy N, Whitehouse A, Downs J. Conceptualizing a quality of life framework for girls with Rett syndrome using qualitative methods. American Journal of Medical Genetics Part A. 2015

3. Harvey A. Therapy for young children with cerebral palsy: what, when, where and how? Invited Commentary. Developmental Medicine and Child Neurology. 2015. Early Online

4. Hyde C, Fuelscher I, Enticott PG, Reid SM and Williams J. Rapid online control to reaching is preserved in children with congenital spastic hemiplegia: evidence from double-step reaching performance. J Child Neurol. 2015; 30 9:1186-1191 IF: 1.666

5. Ianelli M, Harvey A, O'Neill J and Reddihough D. Parental satisfaction with inpatient care of children with cerebral palsy. Journal of Paediatrics and Child Health. 2015 IF: 1.193

6. Imms C, Novak I, Kerr C, Shields N, Randall M, Harvey A, Graham HK and Reddihough DS. Improving allied health professionals' research implementation behaviours for children with cerebral palsy: protocol for before-after study. Implementation Science. 2015; 16:16. IF: 4.12

7. Iorio A, Spencer FA, Falavigna M, Alba C, Lang E, Burnand B, McGinn T, Hayden J, Williams K, Shea B, et al. Use of GRADE for assessment of evidence about prognosis: rating confidence in estimates of event rates in broad categories of patients BRITISH MEDICAL JOURNAL 350:8

8. James S, Stevenson SW, Silove N, Williams K. Chelation for autism spectrum disorder (ASD). Cochrane database of systematic reviews (Online). 2015; 5:CD010766. IF: 6.03

9. Lionti T, Reid SM, White SM and Rowell MM A population-based profile of 160 Australians with Prader-Willi syndrome: trends in diagnosis, birth prevalence and birth characteristics. American Journal of Medical Genetics. 2015; 167:371-378. IF: 2.048

10. McConachie H, Parr JR, Glod M, Hanratty J, Livingstone N, Oono IP, Robalino S, Baird G, Beresford B, Charman T, Jones G, Law J, Le Couteur AS, Macdonald G, McColl EM, Morris C, Rodgers J, Simonoff E, Terwee CB, Williams K. Systematic Review of Tools to Measure Outcomes for Young Children with Autism Spectrum Disorder. Health Technology Assessment. 2015; 19(41):1-506.

11. Meehan E, Freed G, Reid S, Williams K, Sewell J, Rawicki B and Reddihough D. Tertiary paediatric hospital admissions in children and young people with cerebral palsy. Child: Care, Health and Development. 2015; IF: 1.832

12. Meehan E, Harvey A, Reid S, Reddihough DS, Williams K, Crompton KE, Omar S and Scheinberg A. Therapy service use in children and adolescents with cerebral palsy: an Australian perspective. Journal of Paediatrics and Child Health. 2015. IF:1.193

13. Meehan E, Reid SM, Williams K, Freed GL, Babl FE, Sewell JR, Rawicki B and Reddihough DS. Tertiary paediatric emergency department use in children and young people with cerebral palsy. Journal of Paediatrics and Child Health. 2015. IF: 1.193

14. Mei C, Reilly S, Reddihough D, Mensah F, Green J, Pennington L and Morgan AT. Activities and participation of children with cerebral palsy: parent perspectives. Disabil Rehabil. 2015. IF: 1.837

15. Petersen S, Harvey A, Reddihough D and Newall F. Children with cerebral palsy: why are they awake at night? A pilot study. Journal for Specialists in Pediatric Nursing. 2015; 20:98-104. IF: 0.923

16. Randall R, Sciberras E, Brignell A, Ihsen E, Efron D, Dissanayake C, Williams K. Autism spectrum disorder: Presentation and prevalence in a nationally representative Australian sample. Australian and New Zealand Journal of Psychiatry. 2015; IF: 3.41

17. Reddihough D, Meehan E, Stott N and deLacy M. The National Disability Insurance Scheme - a time for real change in Australia. Developmental Medicine and Child Neurology. 2015. IF: 3.292

18. Reid SM. Improving survival in cerebral palsy: where do we go from here? [Invited commentary]. Developmental Medicine and Child Neurology. 2015; 57:703-4 IF: 3.292

19. Reid SM DM, Reddihough DS. Relationship between characteristics on magnetic resonance imaging and motor outcomes in children with cerebral palsy and white matter injury. Research in Developmental Disabilities. 2015; 178-187. IF: 2.735

20. Reid SM, Dagia CD, Ditchfield MR and Reddihough DS. Grey matter injury patterns in cerebral palsy: associations between structural involvement on MRI and clinical outcomes. Dev Med Child Neurol. 2015. IF: 3.292.

21. Reid SM, Meehan E, McIntrye S, Goldsmith S, Badawi N, Reddihough DS and in collaboration with the Australian Cerebral Palsy Register group. Temporal trends in cerebral palsy by impairment severity and birth gestation. Developmental Medicine and Child Neurology. 2015. IF: 3.292

22. Smithers-Sheedy H, Raynes-Greenow C, Badawi N, Reid S, Meehan E, Gibson C, Dale R and CA J. Neuroimaging findings in a series of children with cerebral palsy and congenital cytomegalovirus infection. Infect Disord Drug Targets. 2015; 14:185-90.

23. Taghizadeh N, Davidson A, Williams K, Story D. Autism spectrum disorder (ASD) and its perioperative management. Pediatric Anesthesia. 2015; 25(11). IF: 1.85

24. Thomas SL, Williams K, Ritchie J and Zwi K. Improving paediatric outreach services for urban Aboriginal children through partnerships: views of community based service providers. Child: Care, Health and Development. 2015. IF: 1.832

25. Williams K. Use of GRADE for assessment of evidence about prognosis: rating confidence in estimates of event rates in broad categories of patients. BMJ. 2015; 350. IF: 14.09

26. Williams, K et al. Diagnosing autism: Australian Paediatric Research Network surveys. Journal of Paediatrics and Child Health. In press

27. Williams K. Timely identification of children with autism: Are we asking the right question? Developmental Medicine & Child Neurology. 2015; IF 3.51

28. Williams K, Brignell A, Prior M, Bartak L, Roberts J. Regression in autism spectrum disorders. Journal of Paediatrics and Child Health. 2015; 51(1). IF: 1.15

29. Woolfenden S, Williams K, Eapen V, Mensah F, Hayen A, Siddiqi A, Kemp L. Developmental vulnerability–don't investigate without a model in mind. Child: care, health and development. 2015;41(3):337-45.

2014

30. Baikie G, Ravikumara M, Downs J, Naseem N, Wong K, Percy A, Lane J, Weiss B, Ellaway C, Bathgate K and Leonard H. Gastrointestinal dysmotility in Rett syndrome. Journal of Pediatric Gastroenterology and Nutrition. 2014; 58: 244-51 IF: 2.625

31. Bourke-Taylor H, Cotter C and Stephan R. Complementary, alternative, and mainstream service use among families with young children with multiple disabilities: Family costs to access choices. Phys Occup Ther Pediatr. 2014. IF: 1.418

32. Brignell A, Morgan A, Woolfenden S and Williams K How relevant is the framework being used with autism spectrum disorders today? International Journal of Speech-Language Pathology. 2014; 16: 43-49. IF: 1.412

33. Burns F, Stewart R, Reddihough D, Scheinberg A, Ooi K and Graham HK . The cerebral palsy transition clinic: administrative chore, clinical responsibility, or opportunity for audit and clinical research? Journal of Children's Orthopaedics. 2014; 8:203-213.

34. Cooper M, van Schilfgaarde K, De Mel G and Rajapaksa S. Identification of human parechovirus-3 in young infants within rural Victoria. Journal of Paediatrics and Child Health. 2014; 50:746-747. IF: 1.193

35. Crompton KE, Elwood N, Kirkland M, Clark P, Novak I and Reddihough D. Feasibility of trialling cord blood stem cell treatments for cerebral palsy in Australia. Journal of Paediatrics and Child Health. 2014; 50:540-44. IF: 1.193

36. Dadds MR, MacDonald E, Cauchi A, Williams K, Levy F and Brennan J. Nasal oxytocin for social deficits in childhood autism: A randomized controlled trial. Journal of Autism and Developmental Disorders. 2014; 44: 521-31 IF: 3.384

37. Eapen V, Woolfenden S, Williams K, Jalaludin B, Dissanayake C, Axelsson EL, Murphy E, Eastwood J, Descallar J, Beasley D, Rudi, Short K, Silove N, Einfeld S and Prior M. Are you available for the next 18 months-methods and aims of a longitudinal birth cohort study investigating a universal developmental surveillance program: the 'Watch Me Grow' study. BMC Pediatrics. 2014; 14; 234 IF: 1.918

38. Freilinger M, Bohm M, Lanator I, Vergesslich-Rothschild K, Huber WD, Anderson A, Wong K, Baikie G, Ravikumara M, Downs J and Leonard H. Prevalence, clinical investigation, and management of gallbladder disease in Rett syndrome, Developmental Medicine and Child Neurology. 2014; 56: 756-62. IF: 3.292

39. Gilson K, Davis E, Reddihough D, Graham K and Waters E. Quality of life in children with cerebral palsy: Implications for practice Journal of Child Neurology. 2014; 29: 1134-1140 IF: 1.666

40. Harvey A, Baker L and Williams K Non-surgical prevention and management of scoliosis for children with Duchenne muscular dystrophy: What is the evidence? Journal of Paediatrics and Child Health. 2014; 50; E3-9 IF: 1.193

41. Hayles E, Jones A, Harvey D, Plummer D and Ruston S. Delivering healthcare services to children with cerebral palsy and their families: a narrative review Health Soc Care Community. 2014. IF: 1.369

42. Mei C, Reilly S, Reddihough D, Mensah F and Morgan A. Motor speech impairment, activity, and participation in children with cerebral palsy. International Journal of Speech-Language Pathology. 2014; 16: 427-435 IF: 1.412

43. Moldrich R and Marraffa C. Approaching autism. Medical Student Journal. 2014; 4: 99-103

44. Morgan P, Murphy A, Opheim A, Pogrebnoy D, Kravtsov S and McGinley J. The safety and feasibility of an intervention to improve balance dysfunction in ambulant adults with cerebral palsy: A pilot randomized controlled trial. Clin Rehabil. 2014 IF: 2.18

45. Mouti A, Reddihough D, Marraffa C, Hazell P, Wray J, Lee K and Kohn M. Fluoxetine for Autistic Behaviors (FAB trial): study protocol for a randomized controlled trial in children and adolescents with autism. Trials. 2014; 15: 230 IF: 2.117

46. Randall M, Imms C, Carey L and Pallant J. Rasch analysis of the Melbourne Assessment of Unilateral Upper Limb Function. Developmental Medicine and Child Neurology. 2014; 56: 665-72 IF: 3.292

47. Reid S. Trends in cerebral palsy survival: are health measures really making a difference? [Invited commentary]. Developmental Medicine and Child Neurology. 2014. IF: 3.292

48. Reid SM, Dagia CD, Ditchfield MR, Carlin JB and Reddihough DS. Population-based studies of brain imaging patterns in cerebral palsy Developmental Medicine and Child Neurology. 2014: 56: 222-232. IF: 3.292

49. Reid SM, Dagia CD, Ditchfield MR, Carlin JB, Meehan EM and Reddihough DS. An Australian population study of factors associated with MRI patterns in cerebral palsy. Developmental Medicine and Child Neurology. 2014; 56: 178-184 IF: 3.292

50. Rinehart N, May T, McGillivray J, Papadopoulos N, Sciberras E, Williams K and Hiscock H Sleep disturbance in autism spectrum disorders: Recent advances in research and practice. InPsych Magazine Australian Psychological Society. 2014; 36: 2

51. Sherwell S, Reid S, Reddihough D, Wrennall J, Ong B and Stargatt R. Measuring intellectual ability in children with cerebral palsy: can we do better? Research in Developmental Disabilities. 2014; 35: 2558-2567. IF: 2.735

52. Smithers-Sheedy H, Raynes-Greenow C, Badawi N, McIntyre S, Jones C and ACPR Group. Congenital cytomegalovirus is associated with severe forms of cerebral palsy and female gender in an Australian population cohort study. Developmental Medicine and Child Neurology. 2014; 56: 846-852. IF: 3.292

53. Spreckley M. Inclusive programming. Early Years Journal Belonging. 2014; 3: 24-25. IF: 1.369

54. Vivanti G, Prior M, Williams K and Dissanayake C. Predictors of outcomes in autism intervention: Why don't we know more? Frontiers in Pediatrics. 2014. 2 Article 58.

55. Williams K, Woolfenden S, Roberts J, Rodger S, Bartak L and Prior M. Autism in context 2: Assessment, intervention and services in Australia. Journal of Paediatrics and Child Health. 2014; 50: 341-346. IF: 1.193

56. Williams K, Woolfenden S, Roberts J, Rodger S, Bartak L and Prior M Autism in context 1: Classification, counting and causes Journal of Paediatrics and Child Health. 2014; 50: 335-340. IF: 1.193

57. Woolfenden S, Eapen V, Williams K, Hayen A, Spencer N and Kemp L. A systematic review of the prevalence of parental concerns measured by the Parents Evaluation of Developmental Status (PEDS) indicating developmental risk. BMC Pediatrics. 2014; 14: 231. IF: 1.918

58. Woolfenden S, Williams K, Eapen V, Mensah F, Hayen A, Siddiqi A and Kemp L. Developmental vulnerability – don't investigate without a model in mind Child: Care, Health and Development. 2014. IF: 1.832

2013

59. 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. IF 2.625

60. 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.IF 2.486

61. 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 IF 2.735

62. 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

63. 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

64. 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. IF 1.193

65. Harvey A, Randall M, Reid SM, et al. Children with cerebral palsy and periventricular white matter injury: does gestational age affect functional outcome? Res Dev Disabil 2013; 34:2500-06. IF 2.735

66. Leonard, H., Ravikumara, M., Baikie, G., Naseem, N., Ellaway, C., Percy, A., Abraham, S., Geerts, S., Lane, J., Jones, M., Bathgate, K. & Downs, J. Assessment and management of nutrition and growth in Rett syndrome. Journal of Pediatric Gastroenterology and Nutrition, 2013.57, 451-460. IF 2.625

67. Levac DE, Galvin J. When is virtual reality "therapy"? . Arch Phys Med Rehabil 2013; 94:795-98. IF 2.441

68. Lionti, T., Reid, S. M., Reddihough, D. S. & Sabin, M. Monitoring height and weight: Findings from a developmental paediatric service. Journal of Paediatrics and Child Health, 2013. 49, 1063-1068. IF 1.193

69. Mesterman R, Gorter JW, Harvey A, et al. Botulinum toxin type-A in children and adolescents with severe cerebral palsy: A retrospective chart review. J Child Neurol 2013. IF 1.666

70. O'Callaghan ME, MacLennan AH, Gibson CS, et al. Genetic and clinical contributions to cerebral palsy: A multi-variable analysis. J Paediatr Child Health 2013; 49:575-81. IF 1.193

71. Randall M, Harvey A, Imms C, Lee K, Reid S. Reliable classification of functional profiles and movement disorders of children with cerebral palsy. Phys Occ Ther Ped 2013; 33:342-52. IF 1.869

72. Reddihough D, Jiang B, Lanigan A, et al. Social outcomes of young adults with cerebral palsy. J Intellect Dev Disabil 2013; DOI: 10.3109/13668250.2013.788690 IF 1.061

73. Reid SM, Dagia CD, Ditchfield MR, Carlin JB, Reddihough DS. Systematic review of population-based studies of brain imaging patterns in cerebral palsy. Dev Med Child Neurol 2013; DOI: 10.1111/dmcn.12228. IF 3.292

74. Reid SM, Walstab JE, Chong D, Westbury C, Reddihough DS. Secondary effects of botulinum toxin injections into the salivary glands for the management of paediatric drooling. J Craniofac Surg 2013; 24:28-33. IF 0.676

75. Riess S, Reddihough DS, Howell KB, et al. ALG3-CDG (CDG-Id): Clinical, biochemical and molecular findings in two siblings. Mol Genet Metab 2013; doi.org/10.1016/j.ymgme.2013.05.020. IF 2.827

76. Taylor NF, Dodd KJ, Baker RJ, et al. Progressive resistance training and mobility-related function in young people with cerebral palsy: a randomized controlled trial. Dev Med Child Neurol 2013; 55:806-12. IF 3.292

77. Terrett G, White R, Spreckley M. A preliminary evaluation of the parent-child Mother Goose program in relation to children's language and parenting stress. Journal of Early Childhood Research 2013; 11:16-26.

78. Williams, K., Brignell, A., Randall, M., Silove, N. & Hazell, P. Selective serotonin reuptake inhibitors for treating people with autism spectrum disorders. Cochrane Database of Systematic Reviews, 2013. Issue 8. Art. No.: CD004677. IF 5.939

79. Williams K, Perkins D, Wheeler D, Hayen A, Bayl V. Can questions about social interaction correctly identify preschool aged children with autism. J Paediatr Child Health 2013; 49:E167-74.IF 1.193

80. Woolfenden, S., Goldfeld, S., Raman, S., Eapen, V., Kemp, L. & Williams, K. 2013. Inequity in child health: the importance of early childhood development. Journal of Paediatrics and Child Health, doi: 10.1111/jpc.1217 IF 1.193

81. Yaplito-Lee J, Riess S, Reddihough DS, et al. Clinical, biochemical and molecular findings in two siblings. Mol Genet Metab 2013. IF 2.827

2012

82. Barks L, Davenport P. Wheelchair components and pulmonary function in children with cerebral palsy. Assist Technol 2012; 24:78-86. IF 1.679

83. Bolch CE, Davis PG, Umstad MP, Fisher JR. Multiple birth families with children with special needs: a qualitative investigation of mothers' experiences. Twin Res Hum Gen 2012; 15:503-15. IF 1.918

84. Contopoulos-Ioannidis D, Seto I, Hamm M, et al. Empirical evaluation of age groups and age-subgroup analyses in pediatric randomized trials and pediatric meta-analyses. Pediatrics 2012; 129:S161-S84. IF 5.297

85. Forrester M, Mihrshahi , Waugh M, et al. Conscious sedation or general anaesthetic for intramuscular BoNT-A injections in children – a two centre cross-sectional prospective audit [letter]. Eur J Paed Neurol 2012; 16:215 -17. IF 1.934

86. Greaves S, Imms C, Krumlinde-Sundholm L, Dodd K, Eliasson AC. Bimanual behaviours in children aged 8-18 months: A literature review to select toys which elicit the use of two hands. Res Dev Disabil 2012; 33:240-50. IF 2.735

87. Harvey A, Rosenbaum P, Hanna S, Yousefi-Nooraie R, Graham H. Longitudinal changes in mobility following single event multilevel surgery in ambulatory children with cerebral palsy. J Rehabil Med 2012; 44:137-43. IF 1.683

88. Hurwitz R, Blackmore R, Hazell P, Williams K, Woolfenden S. Tricylic antidepressants for Autism Spectrum disorders Cochrane Database Syst Rev 2012. IF 5.939

89. Lionti T, Reid S, Rowell M. The Victorian Prader-willi Syndrome Register Report 2012. 2012.

90. Lionti T, Reid SM, Reddihough DS, Sabin M. Monitoring height and weight: Findings from a developmental paediatric service. J Paediatr Child Health 2012; doi:10.1111/j.1440-1754.2012.02470.x.

91. Lionti T, Reid SM, Rowell MM. Prader-Willi Syndrome in Victoria: mortality and causes of death. J Paediatr Child Health 2012; 48:506-11. IF 1.193

92. McMullan S, Chin R, Froude E, Imms C. 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 2012; 59:197-208. IF 0.827

93. Morrow AM, Hayen A, Quine S, Scheinberg A, Craig JC. A comparison of doctors', parents' and children's reports of health states and health-related quality of life in children with chronic conditions. Child Care Health Dev 2012; 38:186-95. IF 1.832

94. Randall MJ, Imms C, Carey L. Further evidence of validity of the modified Melbourne Assessment for neurologically impaired children aged 2 to 4 year. Dev Med Child Neurol 2012; 54:424-28. IF 3.292

95. Reid SM, Carlin JB, Reddihough DS. Survival of individuals with cerebral palsy born in Victoria, Australia, between 1970 and 2004. Dev Med Child Neurol 2012; 54:353-60. IF 3.292

96. Reid SM, Carlin JB, Reddihough DS. Survival of individuals with cerebral palsy born in Victoria, Australia, between 1970 and 2004 – Reid et al reply [letter]. Dev Med Child Neurol 2012; 54:867-8. IF 3.292

97. Reid SM, McCutcheon J, Reddihough DS, Johnson H. Prevalence and predictors of drooling in 7 to 14 year old children with cerebral palsy: a population study. Dev Med Child Neurol 2012; 54:1032-36. IF 3.292

98. Scheinberg A. Early Intervention for children with disability – Position Statement Working party for RACP. 2012.

99. Seto I, Foisy M, Arkison B, Klassen T, Williams K. The evaluation of an evidence-based clinical answer format for pediatricians. BMC Pediatrics 2012; 12:34. IF 1.918

100. Shore B, Yu X, Desai S, et al. Adductor surgery to prevent hip displacement in children with cerebral palsy: The predictive role of the gross motor function classification system. J Bone Joint Surg Am 2012; 94:326-34. IF 2.801

101. Williams J, Anderson V, Reid SM, Reddihough D. Motor imagery of the unaffected hand in children with spastic hemiplegia. Dev Neuropsychol 2012; 37:84-97. IF 2.67

102. Williams K, Marraffa C. No evidence yet to support omega-3 fatty acids as a treatment for autism. J Paediatr Child Health 2012; 48:457-546. IF 1.193

103. Williams K, Tang M. Probiotics may prevent upper respiratory tract infections, but should we recommend them? . J Paediatr Child Health 2012; 48:942-43. IF 1.193

104. Williams K, Thomson D, Seto I, et al. Standard 6: Age groups for pediatric trials. Pediatrics 2012; 129:S153-S60. IF 5.297

105. Williams K, Wray JA, Wheeler DM. (2012) Intravenous Secretin for Autism Spectrum Disorders (ASD) The Cochrane Review. IF 5.939

106. Woolfenden S, Sarkozy V, Ridley G, Coory M, Williams K. A systematic review of two outcomes in autism spectrum disorder - epilepsy and mortality. Dev Med Child Neurol 2012; 54:306-12. IF 3.292

107. Woolfenden S, Sarkozy V, Ridley G, Hayen A, Williams K. A systematic review of the diagnostic stability of autism spectrum disorder. Res Autism Spectr Disord 2012; 6:345-54. IF 2.212

2011

108. Alhusani A, Crosbie J, Shepherd R, Dean C, Scheinberg A. No change in passive muscle stiffness following Botulinum toxin injection to the calf in children with cerebral palsy. Dev Med Child Neurol 2011; 53:553-58. IF 3.292

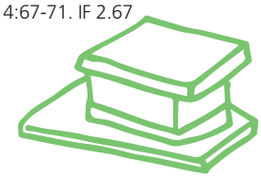
109. Carter M, Roberts J, Williams K, et al. Interventions used by Australian sample of preschool children with autism spectrum disorders. Res Autism Spectr Disord 2011; 5:1033-41. IF 2.212

110. Dobson F, Morris ME, Baker R, Graham HK. Unilateral cerebral palsy: a population-based study of gait and motor function. Dev Med Child Neurol 2011; 53:429-35. IF 3.292

111. Donlau M, Imms C, Mattsson GG, et al. Children and youth with myelomeningocele's independence in managing clean intermittent catheterization in familiar settings. Acta Paediatr 2011; 100:429. IF 1.842

112. Foisy M, Williams K. The Cochrane Library and non-pharmacological treatments for attention deficit hyperactivity disorder in children and adolescents: an overview of reviews. Evid-Based Child Health 2011; 6:283-97.

113. Galvin J, Hewish S, Rice J, Mackay MT. Functional outcome following paediatric stroke. Dev Neurorehabil 2011; 14:67-71. IF 2.67



114. Galvin J, Sakzewski L. Botulinum toxin A in conjunction with occupational therapy reduces spasticity and improves upper limb function and goal attainment in children with cerebral palsy. Australian Occupational Therapy Journal 2011; 58:132-35. IF 0.827

115. Harvey A, Gorter JW. Video gait analysis for ambulatory children with cerebral palsy: why, when, where and how! Gait Posture 2011; 33:501-03. IF 2.299

116. Hoare B, Imms C, Randall M, Carey L. Linking cerebral palsy upper limb measurements to the International Classification of Functioning Disability and Health. J Rehabil Med 2011; 43:987-96. IF 1.683

117. Imms C. Bracing and splinting interventions in the upper limbs of people with cerebral palsy. Dev Med Child Neurol 2011; 53:293-94. IF 3.292

118. James S, Montgomery P, Williams K. Omega-3 fatty acids supplementation for autism spectrum disorders (ASD). Cochrane Library 2011:DOI: 10.1002/14651858.CD007992.pub2. IF 5.939

119. Leonard JM, Cozens AL, Reid SM, et al. Should children with cerebral palsy and normal imaging undergo testing for inherited metabolic disorders? Dev Med Child Neurol 2011; 53:226-32. IF 3.292

120. Leonard JM, Cozens AL, Reid SM, et al. Leonard et al reply [letter]. Dev Med Child Neurol 2011; 53:1161. IF 3.292

121. Macdonald E, Dadds MR, Brennan JL, et al. Safety, side-effects and subjective reactions to intranasal oxytocin: A review of research studies 1990 to 2010. Psychoneuroendocrinology 2011; 36:1114-26. IF 4.944

122. O'Flaherty SJ, Janakan V, Morrow AF, Scheinberg A, Waugh M. Botulinum toxin adverse events and health status in children with cerebral palsy in all GMFCS levels. Dev Med Child Neurol 2011; 53:125-30. IF 3.292

123. Reddihough DS. Cerebral palsy in childhood. Aust Fam Physician 2011; 40:192-96. IF 0.688

124. Reddihough DS, Graham HK. Botulinum toxin type B for sialorrhea in children with cerebral palsy: a randomized trial comparing three doses [commentary]. Dev Med Child Neurol 2011; 53:488-89. IF 3.292

125. Reddihough DS, Reid SM, Plover C. Evaluation of glycopyrrolate in the treatment of chronic drooling. Degen Neuro Neuromusc Dis 2011; 1:3-7.

126. Reid SM, Carlin JB, Reddihough DS. Distribution of motor types in cerebral palsy: how do registry data compare? Dev Med Child Neurol 2011; 53:233-38. IF 3.292

127. Reid SM, Carlin JB, Reddihough DS. Classification of topographical pattern of spasticity in cerebral palsy: a registry perspective. Res Dev Disabil 2011; 32:2909-15. IF 2.735

128. Reid SM, Carlin JB, Reddihough DS. Rates of cerebral palsy in Victoria, Australia, 1970 to 2004: has there been a change? Dev Med Child Neurol 2011; 53:907-12. IF 3.292

129. Reid SM, Carlin JB, Reddihough DS. Using the Gross Motor Function Classification System to describe patterns of motor severity in cerebral palsy. Dev Med Child Neurol 2011; 53:1007-12. 3.292

130. Reid SM, Modak MB, Berkowitz RG, Reddihough DS. A population based study and systematic review of hearing loss in children with cerebral palsy Dev Med Child Neurol 2011; 53:1038-45 IF 3.292

131. Roberts J, Williams K, Carter M, et al. A randomised controlled trial of two early intervention programs for young children with autism: Centre-based with parent program and Home-based. Res Autism Spectr Disord 2011; 5:1553-66. IF 2.212

132. Scheinberg AM. Screening for children born extremely preterm and extremely low birth-weight – a role for health-related quality of life measures/ [commentary]. Dev Med Child Neurol 2011; 53:878-80. IF 3.292

133. Seto I, Arkison B, Williams K. Knowledge management in a small knowledge intensive organisation: research design process at the Cochrane Child Health Field. Knowledge Management Research and Practice 2011; 9:378–84. IF 0.554

134. Sinha Y, Silove N, Hayen A, Williams K. Review. Auditory integration training and other sound therapies for autism spectrum disorders (ASD). Cochrane Database Syst Rev 2011. IF 5.939

135. Srinivasan J, Mink JW. Stereotypies and other developmental hyperkinesias. In: A Albanese, J Jankovic editors. Hyperkinetic Movement Disorders: Differential Diagnosis and Treatment Oxford: Wiley-Blackwell, 2011.

136. Wells J. No easy-fix to bowel incontinence in children. Ostomy Australia 2011; 20.

137. Williams J, Anderson V, Reddihough DS, et al. A comparison of motor imagery performance in children with spastic hemiplegia and developmental coordination disorder. J Clin Exp Neuropsychol 2011; 33:273–82. IF 2.158

138. Williams J, Reid SM, Reddihough D, Anderson V. Motor imagery ability in children with congenital hemiplegia: effect of lesion side and functional level. Res Dev Disabil 2011; 32:740-48. IF 2.735

139. Zdolsek HA, Olesch C, Antolovich G, Reddihough D. Intrathecal baclofen therapy: Benefits and complications. J Intellect Dev Disabil 2011; 36:207-13., IF 1.061

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 the inaugural Chair of the National Disability Insurance Agency, 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 Senior Associate Dean (Engagement) 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 RCH. 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.

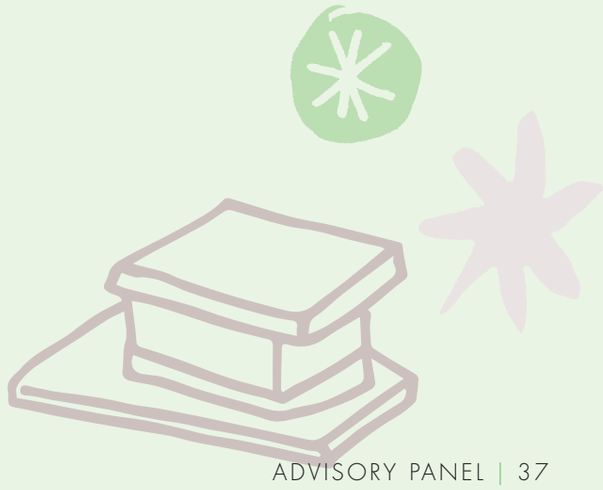
A/PROF ADAM SCHEINBERG

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 RCH, and Director of Critical Care and Clinical Sciences at the Murdoch Childrens Research Institute. Her research group at the RCH, 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 RCH 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.

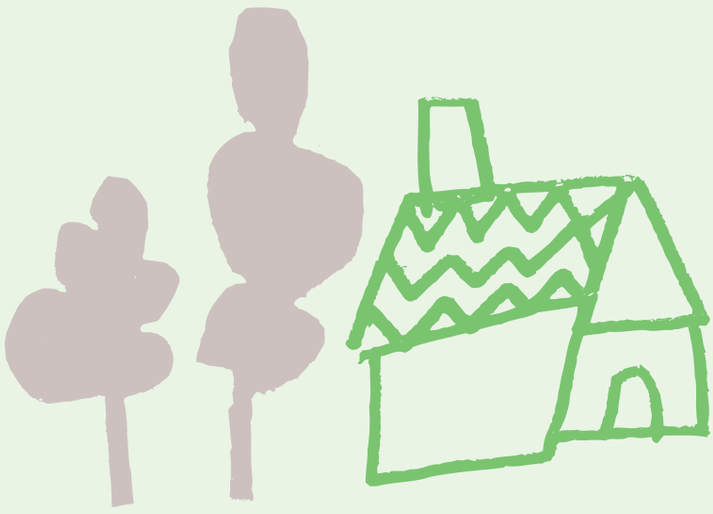
MRS ANNE MCGEARY

Anne McGeary has been raising funds for the RCH 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.

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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