

SOLVE! AT THE RCH

STRATEGIC PLAN 2006-2010

AND

BUSINESS PLAN 2006 AND 2007

July 2006

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EXECUTIVE SUMMARY

- New research to prevent causes, improve treatments for children with disabilities and enhance support for their families is urgently needed.
- In the 0-14 age group, there are 73,507 children in Victoria and 296,400 children in Australia with a disability and the incidence of disability is increasing. A child is born in Australia with cerebral palsy, the most common form of physical disability, every 18 hours and in the majority of cases the cause is unknown.
- Over the past 20 years, the Department of Child Development and Rehabilitation at the Royal Children's Hospital has developed a very strong reputation for its clinical work and support for families, as well as a national and international reputation for disability research. Much of the research has not been fully funded yet has already resulted in significant improvements in the way children with disabilities are treated and major cost savings.
- Major research achievements include development of the Melbourne Assessment of Upper Limb Function for Children with Cerebral Palsy, which is now used internationally to evaluate programs to determine optimal outcomes for children with cerebral palsy; the design and independent evaluation of a new home-based early intervention program that has had remarkable results; eliminating the need for frequent hip X-rays for many children with cerebral palsy; earlier and more effective treatment of infections in children with severe cerebral palsy reducing hospitalisations; and, better treatment of saliva control in children with cerebral palsy leading to increased socialisation and much lower costs of treatment.
- There is also great potential to leverage the work done to date. The Victorian Cerebral Palsy Register contains unique information about all young people with cerebral palsy born in Victoria since 1970. This data is not in the Birth Defects Register, because cerebral palsy often is not evident at birth. The Register provides a very important foundation for future research and planning disability, education and public health services.
- In order to continue to build the national and international significance of the research, the Centre for Developmental Disability Research, known as Solve! At the RCH, has been established. Its aim is to become one of Australia's leading clinically based medical research centres, specialising in developmental disability.
- Solve! At the RCH is governed by the Royal Children's Hospital professional and ethical standards and its own Advisory Panel. It has a strong partnership with the research arm of the Royal Children's Hospital, the Murdoch Childrens Research Institute, as well as universities and disability service providers.
- The 2006 to 2010 Strategic Plan for the Centre for Developmental Disability Research includes key organisational, research and partnership objectives.
- The Organisation Plan includes establishing a Chair of Paediatric Developmental Disability, as well as other significant additions to the research staff.
- The Research Plan includes discovering at least one new pathway that results in cerebral palsy and improving the efficacy and cost efficiency of the interventions that are currently available for children with disabilities. The Partnership opportunities include stronger relationships with universities, NHMRC, trusts and foundations, individuals and the corporate sector.
- The Business Plan for 2006 and 2007 focuses on the immediate organisational and research priorities, building partnerships and preparations for the establishment of a Chair of Paediatric Developmental Disability.

**SOLVE! AT THE RCH—STRATEGIC PLAN 2006-2010 AND
BUSINESS PLAN 2006 AND 2007**

BACKGROUND

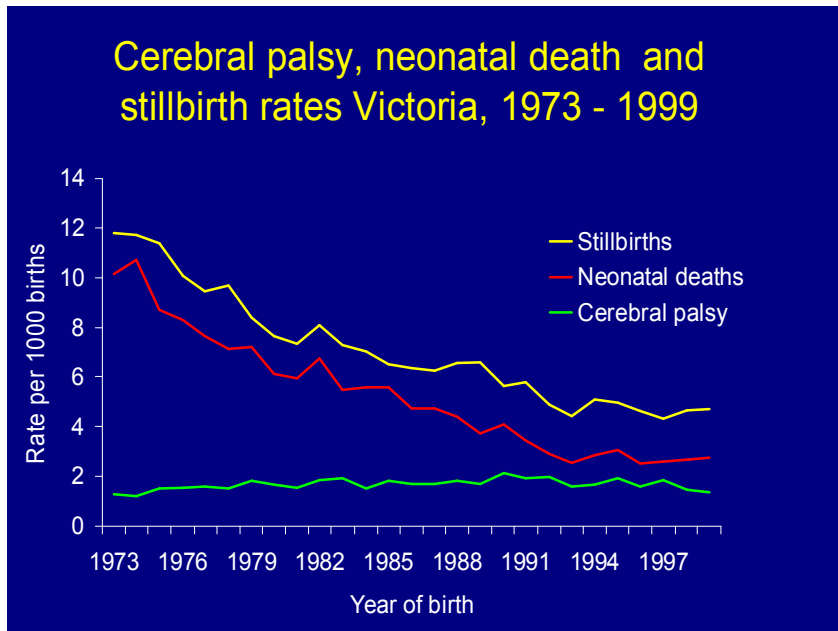
The Incidence and Costs of Disability in Children

There are 296,400 children in the 0-14 age group in Australia with a disability and 73,507 in Victoria. This is approximately 7.6% of children of this age group.

The disabilities include intellectual disability, cerebral palsy, spina bifida, severe visual impairment, hearing impairment, autism spectrum disorders and acquired brain injuries.

Cerebral palsy is the most common cause of physical disability in childhood. It is a disorder of movement and posture resulting from damage to the developing brain. In Victoria there are about 130 new infants born with cerebral palsy each year and there are about 2000 young people under the age of 18 years in Victoria with cerebral palsy.

Over the past 30 years there has been no reduction in the incidence rates of cerebral palsy. Rather there is some evidence that there has been an increased frequency of the condition, due to the survival of low birth weight infants. In stark contrast, over the same period, the incidence of stillbirths and neonatal deaths has declined sharply.



The last major breakthrough in the understanding of the causes of cerebral palsy occurred in the 1960s, when jaundice was identified as the major cause of a particular type of cerebral palsy called athetoid cerebral palsy. Since then newly born children who develop jaundice are treated urgently and the incidence of athetosis due to neonatal jaundice is now extremely low.

The incidence of several other types of disabilities, for example, the autism spectrum disorders, also appear to be increasing.

The management of children with disabilities and chronic conditions is a priority in child health because early intervention is effective and the impact of disability is life long and affects both children and their families. For example, based on current treatments of children with cerebral palsy, 30% will not walk independently, 50-60% will have an intellectual disability, and 40% will have epilepsy. There is therefore much to be gained from further research.

Care of children with cerebral palsy is complex and life long, involving services from a variety of areas including health, education, housing and social security. The physical, emotional and financial costs for parents of children with disabilities are ongoing. The costs in terms of additional family breakdowns are also enormous, with the rates of divorce much higher than the national average for families with children with disabilities.

Prevention of disability, even in only 1-2 cases each year, would result in substantial financial savings, for both the community and the families directly affected.

The financial costs of disability for society include:

- The extra costs associated with medical, allied health and special education requirements, which often involve services being provided from many organisations over many years, if not life;
- The costs associated with Centrelink benefits;
- The loss of opportunity for the individuals to contribute to the open employment pool; and,
- A reduction in family contributions to national production and the work force, as family members become either full or part time carers.

The financial costs of disability for families include:

- Loss of family income due to one parent being unable to work;
- Unmet costs of therapy and education support and equipment, for example the necessity to purchase a van for transportation; and,
- Home modifications, as funding is often only available for a small proportion of what is required.

Department of Child Development and Rehabilitation

The Department of Child Development and Rehabilitation at the Royal Children's Hospital is committed to and has a strong track record in the care of children with cerebral palsy and other disabilities.

The Department currently receives approximately 5000 outpatient visits each year and has established a reputation both for highly personalised care of children and their families and for best practice.

Over this period, the Department has also been conducting research on disability.

Previous Research

The Department of Child Development and Rehabilitation has a very strong national and international reputation for disability research. It collaborates with other leading

groups in Australia and overseas and has a particularly close relationship with the Murdoch Childrens Research Institute.

The research undertaken by the Department of Child Development and Rehabilitation has been published in around 90 articles in refereed journals and in text book chapters. The Department has also presented numerous papers at national and international conferences.

The research has resulted in significant improvements in the way we treat children with disabilities. It has also resulted in cost savings both for the community, as well as emotional and financial benefits for families.

Some of the research achievements to date include:

- The Melbourne Assessment of Upper Limb Function for Children with Cerebral Palsy has been developed and is now used nationally and internationally to evaluate a range of programs, to determine optimal outcomes for children with cerebral palsy. This was a collaborative project with the Department of Occupational Therapy.
- A home-based early intervention program for children with developmental disabilities, in addition to a centre-based program, has been found to make a significant difference to cognitive outcomes, to such an extent that some children receiving the home-based program have been able to enter main stream educational facilities. This project has also resulted in a change of direction in the way that services are delivered from the early intervention centre.
- Programs based on Conductive Education for young children with cerebral palsy have been independently tested and found to be as effective as other approaches and also suit some families well. This approach is now an accepted form of intervention and some of its principles have been successfully incorporated in other therapy approaches. For families there is no longer the need to take their children to Hungary, where this approach to treatment was developed.
- For children with mild cerebral palsy who walk independently, the financial costs, stress and inconvenience of regular X-rays have been prevented. This reflects the findings of a study with the Department of Orthopaedics, which concluded that children with severe cerebral palsy have a high frequency of hip dislocation whilst those with mild cerebral palsy have only a low risk. Therefore regular X-rays are now only necessary in those with severe cerebral palsy.
- Careful screening of the testes of boys with cerebral palsy now takes place (in conjunction with the Department of General Surgery), because boys with cerebral palsy have been found to have an increased frequency of undescended testes. In the future this will result in a reduced frequency of testicular carcinoma and so better long term outcomes.
- Clinicians now look carefully for signs of infection in children with severe cerebral palsy presenting with hypothermia, because these children have been found often to develop hypothermia in the presence of severe infections. Infections are thus treated earlier, reducing hospital stays and costs.
- The beneficial long term health and social effects of saliva control surgery have been documented, while orthodontic appliances have been found to have only a very limited role in saliva control and are therefore now not widely fitted for this purpose.

- Saliva surgery has been found to lead to an increased possibility of caries in incisor teeth, particularly in those with poor dental hygiene. As a result, a dentist works in the saliva control clinic and checks all children prior to saliva control surgery and at regular intervals for up to five years after the intervention. With this increased dental surveillance, the high frequency of dental caries is no longer seen. This has resulted in reduced demand for restorative dental care which is both challenging and costly in many of these young people.
- Clinicians now recommend the use of fluvax in children with severe disabilities, because it has been found that influenza is more likely to have a severe impact on children with disabilities, resulting in much more prolonged hospital stays compared with able bodied children. Preventing pneumonia, a complication of influenza, in even a few children with severe disabilities each year, is already generating enormous cost savings for the hospital sector, and reducing the severe distress and inconvenience that results both for the children themselves and their families.
- A Quality of Life Measure for Children with Cerebral Palsy has been developed recently. It is now being used in assessing outcomes of clinical interventions, leading to more effective treatments, and there has been strong international interest in the Measure.

A complete list of research publications since 1993 is in Appendix 1, while Appendix 2 identifies the sources of research funding totalling more than \$2 million that has been raised in order to fund the research program.

The Department of Child Development and Rehabilitation and Solve! At the RCH also collaborate with external groups, including Latrobe, Deakin and Monash Universities; other hospitals including the Monash Medical Centre and community organisations such as Scope Victoria and the Yooralla Society of Victoria.

The research program also allows an investment in the future by providing opportunities at undergraduate and graduate levels for students to undertake research and deepen their understanding of disability and improve service delivery. This leads to growth in the numbers of highly qualified and experienced professionals in the field of developmental disability, leading to improved health practice.

Today, Solve! At the RCH is in a very strong position to build on the positive outcomes of the past 20 years, to improve the lives for children with disabilities and to better understand and prevent the causes of disability.

The Victorian Cerebral Palsy Register

The Department of Child Development and Rehabilitation has also created a major research and planning data base, through the establishment of the Victorian Cerebral Palsy Register. The Register contains information about all young people with cerebral palsy born in Victoria since 1970. Currently there are 3646 entries and it is the fundamental building block on which research and better practice is being built.

The significance of the Register lies in the fact that cerebral palsy is often not detected at birth and so this condition is not included fully in the Birth Defects Register. Cerebral palsy and other conditions that are often associated with cerebral palsy, such as epilepsy often become apparent at different stages through a person's life. The Register is

updated regularly to reflect these changes and so provides a very important cross-sectional and longitudinal reference framework for organisations working with people with cerebral palsy, researchers, planners and policy makers.

Today, the Register provides:

- An important planning tool for public health, children's services, disability services, education and policy makers as it provides crucial data for planning purposes.
- An essential reference point for medical, dental and other health professionals
- A data base to evaluate outcomes of interventions, and thus advance knowledge so that better help and support can be provided for all children with cerebral palsy and their families.
- Complete data from Victoria for inclusion in a National Cerebral Palsy Register. The National Register will provide the foundation to improve planning and services for people with cerebral palsy and increase developmental disability research efforts throughout Australia.
- A unique data set as it is drawn from a greater population base and over longer time periods than any other cerebral palsy register in the world. It can therefore be used to recruit larger cohorts for more meaningful studies and is recognised internationally as a crucial reference point and tool for research into the causes of cerebral palsy with the eventual aim of prevention.

Maintaining the Victorian Cerebral Palsy Register so that it remains both up to date and comprehensive is one of the key planks on which Solve! At the RCH is being built.

The Way Forward

In 2004 the leadership of the Department of Child Development and Rehabilitation decided that it was time to take its research to the next level and create a Centre of Developmental Disability Research, because of the urgent need to increase knowledge about both the causes of disability in childhood and the outcomes of treatment.

The Centre has been named "Solve! At the RCH" and was formally launched by Sir Gus Nossal on 8 March, 2006. (See www.rch.org.au/cdr for further details.)

SOLVE! AT THE RCH

Mission

To improve outcomes for children with disabilities and to better understand and prevent the causes of disability.

Vision

- To be a centre of excellence conducting high quality research involving different professional groups that will improve knowledge of the causes and outcomes of childhood disability.
- To improve the quality of life for children with disabilities and their families.

- To work collaboratively with other organisations involved in the care of children with disabilities, and to translate research findings into practice.
- To communicate the results of the research and practice to all professionals working with people with disabilities to help promote best practice.
- To raise the profile of research in developmental disabilities.
- To encourage more young graduates to undertake research in developmental disabilities.
- To secure funds for developmental disability research to achieve these goals.

Organisation

The Director of Solve! At the RCH and Head of the Department of Child Development and Rehabilitation is Associate Professor Dinah Reddihough, AO, who has a long and distinguished career as a clinician and in medical research. Associate Professor Reddihough was made an Officer of the Order of Australia in 2005 for services to children with disabilities. (See Appendix 3 for more details.)

A current staff list is shown in Appendix 4.

In addition, the Department of Child Development and Rehabilitation has trained 10 postgraduate students from three Universities over the past 10 years: University of Melbourne (8), Monash University (1), Latrobe University (1). Currently there are two students undertaking higher degrees: one from the University of Melbourne (MD) and one from Monash University (PhD).

Governance

Solve! At the RCH is part of the Royal Children's Hospital and so it is governed by the Hospital's Board and must meet the highest ethical standards.

In addition, the Advisory Panel to Solve! meets regularly to:

- Advise the management of Solve! At the RCH on the initiation, promotion and development of research in development disability, to be conducted by or under the auspices of the Department of Child Development and Rehabilitation and the Murdoch Childrens Research Institute;
- Review all research applications and advise on research priorities within the proposed research budget for Solve! At the RCH;
- Review and consider reports on the research activities and results;
- Assist Solve! At the RCH in its fund development and fund raising activities, to provide both long term and short term funds to support research into developmental disabilities; and,
- Assist the management of Solve! At the RCH in any other areas that the Advisory Panel can contribute.

The members of the Advisory Panel are shown in Appendix 5, with brief biographical details.

Current Research Focus

The current research focus includes:

1. Maintenance of the Victorian Cerebral Palsy Register;
2. Supporting the establishment and maintenance of a National Cerebral Palsy Register; and,
3. The following projects:

Title of project	Status	
Factor V Leiden mutation: a contributory factor for cerebral palsy ?	Nearing completion	
Intrauterine infection: role of the kynurenine pathway in causing perinatal brain damage and multi-organ failure	Nearing completion	
The prevalence of bowel disorders in autism	Nearing completion	
Botulinum Toxin A therapy in the management of children with cerebral palsy (upper limb study)	Nearing completion	
Life expectancy in cerebral palsy	Nearing completion	
Development of a health-related quality of life instrument for children with cerebral palsy	Nearing completion	
Early childhood intervention: do more intensive services improve outcomes for children with developmental delay and their families?	Nearing completion	
MRI findings in a recent cohort of children with cerebral palsy	To be completed in 2006	
“VicCPChild” – Victorian prospective cohort study of children with cerebral palsy	Ongoing	
The development of a database for children with Prader Willi Syndrome	Ongoing	

Quality of life of individuals with Prader Willi syndrome	New project	
The role of Botulinum toxin therapy for children with saliva control problems	In progress, projected to be complete early 2007	
Evaluation of the “Mother Goose” program	New project starting, will take about 2 years	
Culture, coping and marital adjustment of parents of children with disability	To be completed 2006	
Aetiology of a cohort of children with ataxic cerebral palsy	To be completed in 2006	
Attitudes towards Down Syndrome in Australia and Botswana (AMS Student)	To be completed in 2006-07	
Validating the scale for frequency / severity of saliva control problems	To be completed in 2006	
Assessment of swallowing in young people with saliva control problems	To be completed in 2006	

STRATEGIC PLAN—2006 TO 2010

Organisational Plan—2006 to 2010

The key staffing objectives for the next 5 years are to:

- Create a Chair of Paediatric Developmental Disability to lead the research effort; and,
- Attract a team of research fellows, graduates and undergraduates in the fields of medicine and allied health, to specialise in the field of Developmental Disability.

A Chair of Paediatric Developmental Disability would be the first in Australia and make a major contribution to meeting the Mission and Vision for Solve!

The creation of a Chair of Paediatric Developmental Disability would also allow Associate Professor Reddiough to increase her research time. It is anticipated that she would substitute 3 research sessions per week for 3 clinical sessions to bolster her research contribution to Solve! when the professorial position is created. The new Chair would take on her clinical work, so that all research remains clinically based.

A Chair of Paediatric Developmental Disability is a major investment. It would attract a salary of around \$200,000 per annum or perhaps even higher to attract the right international candidate. In addition, the new Chair will be expected to undertake a part-time clinical load and will need to be paid for this medical time. The estimated cost is \$90,000 per annum. It is also forecast that there will be further costs of around \$100,000 per annum, to cover secretarial support, a research assistant and other on-costs. Within five years, the incumbent would be expected to raise some of the costs associated with the position, and attract a growing team of research staff, through competitive grants from NHMRC and elsewhere.

Research Plan—2006 to 2010

The key research objectives for the next 5 years are to:

- Maintain the Victorian Cerebral Palsy Register and establish it as a key public health and medical research tool;
- Make a major contribution to the establishment and maintenance of the Australian Cerebral Palsy Register;
- Deepen the research partnerships with Murdoch Childrens Research Institute, Melbourne, Monash, Latrobe and Deakin Universities;
- Discover at least one new pathway that results in cerebral palsy;
- Improve the evidence available about the efficacy of the various interventions that are available for children with disabilities by conducting randomised trials;
- Improve the treatment of poor saliva control; and,
- Gain a deeper understanding of the strategies necessary to improve participation and quality of life for children with cerebral palsy and their families.

Partnership Opportunities—2006 to 2010

Solve!, through the Department of Child Development and Rehabilitation, has a long and successful track record of building partnerships and successfully raising funds for research through competitive grants and other fund raising.

These efforts will be built on through:

- *Named Chair in Paediatric Developmental Disability and University Partnership*

A major fund raising drive to raise \$1 million to cover the Chair of Paediatric Developmental Disability for the first five years, possibly from a trust, foundation or very wealthy donor who might be attracted to creating a Named Chair in their honour.

A partnership with a university, with an interest in building a specialisation in developmental disability, and which would be prepared to cover the on-costs for the Chair of Paediatric Developmental Disability.

- *Trusts and Foundations*

Build on the existing relationships and develop new partnerships with trusts and foundations through:

- Attracting support for specific research projects of around \$60,000 per annum;
- Seeding support with the objective of attracting future NHMRC and other competitive grants; and,
- Responding to the trend for trusts and foundations to support more strategic projects and provide multi-year funding, which could lead to much more significant improvements in the understanding of the causes of developmental disability and in the treatment of children with disabilities.

- *NHMRC and Other Competitive Research Grants*

Build a strong research team which will attract competitive grants through NHMRC and elsewhere, with a target of \$200,000 per annum by 2010.

Develop stronger relationships with other organisations that are interested in building the pool of funds available for developmental disability research.

- *Corporate Partnerships*

Corporate partnerships, totalling \$50,000 per annum by 2010, with companies which see a reduction in disability and improving outcomes for children with disability as a key part of their corporate social responsibilities.

- *Recurrent CP Register Funding*

Attract recurrent government and research funding to meet the full costs of the Victorian Cerebral Palsy Register of \$70,000 per annum (indexed for inflation), which will secure the Register's central contribution to public health planning and disability research.

- *Donations and Bequests Program*

Attract wealthy individuals with an interest in supporting research into developmental disability, over a multi-year period as well as single donations and bequests. A target of \$50,000 per annum by 2010 has been set.

- *Growing the Supporter Base and Fund Raising Program*

Grow the fund raising efforts through the Auxiliaries of the Royal Children's Hospital, which are committed to supporting Solve!, to provide \$40,000 per annum by 2010 compared with an average of \$25,000, currently.

Generate additional fund-raising through the Solve! website, work place giving and the Royal Children's Hospital Foundation.

Hold annual fund-raising events, to raise \$10,000, rising to \$20,000 per annum, over the next 5 years.

BUSINESS PLAN—2006 AND 2007

Organisational Plans—2006 and 2007

The immediate plans are to increase the numbers of postgraduate students by improving links with Universities and encouraging their students to undertake research studies in developmental disability.

The target is to have 3 postgraduate students and 1 research fellow by end 2007, compared with 1 PhD and 1 MD student at the moment. However, these students require considerable support and this places time pressures on clinical and research staff who already have very full workloads. Therefore the scope to expand the research complement will be limited until the Chair of Paediatric Developmental Disability is established.

Therefore, the plans to establish a Chair of Paediatric Developmental Disability are an immediate high priority, with a view to creating this professorial position during 2008.

Research Plans—2006 and 2007

The continued maintenance and development of the Victorian Cerebral Palsy Register and the building of an Australian Cerebral Palsy Register will be the highest priority, because quality research cannot be undertaken without a reliable data base.

The specific research topics which will be prioritised for 2006 and 2007 include to:

- Examine the role of the Factor V Leiden mutation in the genesis of cerebral palsy and explore whether blood group incompatibility, particularly rhesus factor, is playing a new role.
- Complete the evaluation of the Mother Goose program.
- Develop a tool to measure saliva control in children with developmental disabilities and to build the findings to date to improve the management of poor saliva control.
- Complete and publish the randomised study of the effectiveness of botulinum toxin injections into the salivary glands to reduce drooling.
- Develop a better understanding of the relationship between cerebral palsy and low birth weight in conjunction with a UK group.
- Study the morbidity and mortality of the Victorian cohort of individuals with cerebral palsy.
- Complete and publish the study of the role of quinolinic acid on the pathway to periventricular leucomalacia in cerebral palsy.
- Develop an understanding of the respiratory health of young people with cerebral palsy.
- Collect more information about the contribution of MRI in the genesis of cerebral palsy.
- Study the effects of epilepsy in cerebral palsy with a view to providing better treatment and advice for parents.
- Study the long term outcome of adults with cerebral palsy born between 1/1/76 and 31/12/85.

- Investigate the relationship between IVF and cerebral palsy.

Partnership Opportunities—2006 and 2007

The major partnership objectives for 2006 and 2007 are to:

- *Named Chair in Paediatric Developmental Disability and University Partnership*

Negotiate and agree funding and partnership arrangements, totalling \$300,000 per annum for five years, necessary to establish a Chair of Paediatric Developmental Disability.

- *Trusts and Foundations*

Continue to apply to trusts and foundations for the support of particular projects, with an aim of receiving support of \$80,000 per annum in 2007.

Attract seed funding in order to be more successful in NHMRC grants in 2008 and beyond.

Establish at least one major multi-year strategic partnership with a trust or foundation, with the objective of significantly improving either an aspect of the treatment or investigating a particular cause of developmental disability.

- *NHMRC Research Grants*

Win competitive grants through NHMRC and other sources of \$80,000 for 2008.

- *Corporate Partnerships*

Build a strong working relationship with the Victorian Medical Insurance Agency (VMIA), to ensure that its support of \$35,000 per annum for the Victorian Cerebral Palsy Register will be extended for a further two years at the review date in 2009 and explore additional opportunities to partner with the VMIA.

Develop at least one other corporate partnership, with a view to attracting a similar level of support to the partnership with the VMIA, by end 2007.

- *Recurrent CP Register Funding*

Build on the report funded by the William Buckland Foundation, “Congenital Childhood Disability Registers in Victoria: How can sustainable funding be achieved?” in order to build partnerships with governments. The Victorian Cerebral Palsy Register has the potential to be an important public health, children services, disability and education planning tool. The plan is to work with to embed the Register into their planning processes and achieve part funding by government on a recurrent basis.

- *Donations and Bequests Program*

Attract wealthy individuals with an interest in supporting research into developmental disability, with a view to attracting support of \$30,000 in 2007.

- *Growing the Supporter Base and Fund Raising*

Continue to encourage the Auxiliaries of the Royal Children's Hospital which are committed to supporting Solve! and attract funding of \$30,000 in 2007.

Establish a web-site for Solve! and ensure that it is kept up to date.

Prepare a newsletter for Solve! and develop regular communications with supporters, potential supporters and clients of the Department of Child Development and Rehabilitation and their families and other interested groups, for example, the Cerebral Palsy Support Network.

Build a community supporter base and on-line giving program which reaches 500 potential supporters and raises \$5,000 per annum by end 2007.

Hold The Dress Revival in 2006 and another special fund raising event in 2007.

FINANCIAL FORECASTS—2006 TO 2010

The detailed financial forecasts are shown in Appendix 6.

The plan is to build the research budget from its current level of just over \$200,000 to around \$1.0 million.

The major sources of funds are expected to be support for the Chair of Paediatric Developmental Disability, trusts and foundations, competitive grants (NHMRC) and the Royal Children's Hospital/MCRI. Corporate, government and individual support are also expected to make a valuable contribution, with continuing strong support from the Auxiliaries.

The major areas of expenditure will be salaries, especially for the Chair of Paediatric Developmental Disability.

APPENDIX 1: ARTICLES IN REFERRED JOURNALS AND BOOKS, 1993-2006

DS Reddihough

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CM Marraffa

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APPENDIX 2: RESEARCH GRANTS: 1993-2005

1993	Financial Markets Foundation for Children	DS Reddihough	Efficacy of Conductive Education for Young Children with Cerebral Palsy.	\$55,800 (over 2 years)
1993	The Jack Brockhoff Foundation	DS Reddihough	Efficacy of Conductive Education for Young Children with Cerebral Palsy.	\$20,000
1993	Health, Housing and Community Services Research and Development Grant	G Smith DS Reddihough	Further investigations of an assessment of the quality of upper limb function in children with neurological impairment	\$15,000
1994	ANZ Trustees	DS Reddihough	Efficacy of Conductive Education for Young Children with cerebral palsy	\$20,000
1994	Health, Housing and Community Services Research and Development Grant	D Glaun DS Reddihough P Pattison K Collins	Differences between parents' and professionals' understanding of developmental disability: implications for services	\$15,716
1995	Royal Children's Hospital Research Foundation	DS Reddihough HK Graham AT McCoy GJ Coleman	The effect of Botulinum A therapy in young children with cerebral palsy.	\$60,000
1996	National Health and Medical Research Council	DS Reddihough R Bell N Beischer	Antenatal and perinatal antecedents of spastic cerebral palsy	\$101,214
1996	Royal Children's Hospital Research Foundation	C Olesch DS Reddihough HK Graham A McCoy	Oxygen consumption in cerebral palsy after multilevel surgery	\$14,421
1996	Royal Children's Hospital Research Foundation	G Baikie DS Reddihough A Olinsky	Inhalation pneumonitis and respiratory acidosis in cerebral palsy	\$20,018

1997	Financial Foundations Markets for Children	DS Reddihough	Botulinum Toxin A therapy in the management of children with cerebral palsy	\$73,744
1997	Royal Children's Hospital Research Institute	HK Graham R Boyd G Natrass DS Reddihough A McCoy	The use of a variable hip abduction brace and botulinum toxin A in the conservative management of hip dysplasia in children with cerebral palsy	\$52,800
1998	Royal Children's Hospital Research Institute	DS Reddihough	Further development of the Victorian Cerebral Palsy Register	\$10,000
1998	National Health & Medical Research Council	HK Graham RN Boyd DS Reddihough GR Natrass	A multicentre randomised trial of Botulinum toxin A and bracing in the management of hip problems in cerebral palsy	\$74,577
1998	The Lynne Quayle Charitable Trust Fund	DS Reddihough	The Victorian Cerebral Palsy Register	\$10,000
1998	Hugh D.T.Williamson Foundation	DS Reddihough HK Graham A McCoy	Botulinum Toxin A therapy in the management of children with cerebral palsy	\$66,380
1999	The R.E.Ross Trust	DS Reddihough	The Victorian Cerebral Palsy Register	\$15,000
1999	Royal Children's Hospital Research Institute	DS Reddihough J Halliday H Ekert M Ditchfield K Byron	Factor V Leiden mutation: a contributory factor for cerebral palsy?	\$46,666
1999	Royal Children's Hospital Research Institute	DS Reddihough A Rickards J Hutchinson	Early childhood intervention: do more intensive services improve outcomes for children with developmental delay and their families?	\$48,000
2000	The Ian Potter Foundation	DS Reddihough	The use of the ISMAR, an orthodontic device, to increase eating, speaking and saliva control skill in	\$10,000

			children with cerebral palsy	
2000	National Health & Medical Research Council	DS Reddihough J Halliday H Ekert M Ditchfield K Byron	Factor V Leiden mutation: a contributory factor for cerebral palsy?	\$72,500
2000	Murdoch Childrens Research Institute	DS Reddihough A Rickards J Hutchinson	Early childhood intervention: do more intensive services improve outcomes for children with developmental delay and their families?	\$55,123
2000	The Jack Brockhoff Foundation	DS Reddihough A Rickards	Early childhood intervention: do more intensive services improve outcomes for children with developmental delay and their families?	\$64,332
2000	Murdoch Childrens Research Institute	DS Reddihough S Brennecke HK Graham J Halliday S Reilly M Galea C Imms N Kilpatrick A McCoy M Zacharin	The Victorian Collaborative Cerebral Palsy Project	\$150,000 per year for 3 years
2001	Murdoch Childrens Research Institute	C.Olesch D.Reddihough HKGraham C.Imms	Botulinum toxin A in the hemiplegic upper limb: a randomised control trial	\$30,000
2002	The R.E.Ross Trust	D.Reddihough	Infants at risk of cerebral palsy: early identification and treatment	\$15,000
2002	The Sunshine Foundation	D.Reddihough	Improving the comfort, care and quality of life for children with severe cerebral palsy	\$4,000
2002	Perpetual Trustees (J&R McGauran Charitable Trust)	D.Reddihough	Better quality of life for disabled children by improving saliva control	\$4,773

2002	The Jack Brockhoff Foundation	D.Reddihough	Early childhood intervention: do more intensive services improve outcomes for children with developmental delay and their families?	\$22,540
2002	Murdoch Childrens Research Institute	C.Olesch C.Imms B.Scoullar	Does Botulinum toxin-A therapy in the upper limb enhance occupational therapy outcomes for children with cerebral palsy?	\$20,000
2003	The Perpetual Trustees (The J & Hope Knell Trust)	D.Reddihough	Improving the care of young people with spasticity	\$9,666
2003	The William Buckland Foundation	D. Reddihough HK Graham R.Boyd	The Victorian Cerebral Palsy Surveillance Program	\$105,975
2004	Murdoch Childrens Research Institute	D.Reddihough	Cerebral Palsy Register	\$50,000
2004	National Health and Medical Research Council 284514	Waters E, Boyd R, Reddihough D, Mackinnon A, Graham HK	Development of a health-related quality of life instrument for children with cerebral palsy	2004 \$63,500 2005 \$48,875
2004	National Health and Medical Research Council 284512	Inder T, Boyd R, Doyle R, Reddihough D.	Randomised trial of preventative care at home for preterm infant	\$190,750, \$212,675, \$111,264, \$74,638
2004	Murdoch Childrens Research Institute	Reddihough D, Reid S, Halliday J, Wallace E, Manuelpillai U	New pathways to cerebral palsy: the role of intrauterine infection and quinolinic acid	\$38,000
2004	Perpetual Trustees	Reddihough D,	Life expectancy of children with cerebral palsy	\$12,486

2004	Murdoch Childrens Research Institute	Boyd RN, Reddihough D, Graham HK, Leventer R, Krageloh Mann I, Wolfe R	The VicCPChild project	\$50,000
2005	Telstra Community Development Fund	Boyd RN, Reddihough D, Graham HK, Leventer R, Krageloh Mann I, Wolfe R	The VicCPChild project	\$110,000
2005	Grosvenor Settlement	Reddihough D	Partnerships to empower families	\$20,000
2005	The Marian & E.H.Flack Trust	Reddihough D	Saliva control: improving a difficult problem	\$40,326

APPENDIX 3: ASSOCIATE PROFESSOR DINAH REDDIHOUGH, AO, DIRECTOR OF SOLVE! AT THE RCH AND HEAD OF THE DEPARTMENT OF CHILD DEVELOPMENT AND REHABILITATION

In 2005, Associate Professor Dinah Reddihough was appointed an Officer in the General Division of the Order of Australia. The Citation was:

For service to medicine, particularly to children with cerebral palsy, and to research.

The detailed Citation stated:

“Over many years, Associate Professor Dinah Susan Reddihough has devoted her life to research, patient care and improving services to children with disabilities.

Professor Reddihough has been Director of the Department of Child Development and Rehabilitation at the Royal Children’s Hospital, Melbourne since 1986, although the Department has benefited from her fundraising prowess since 1983. Her interests and expertise cover a variety of fields including:

- Providing an outstanding level of care to babies, children and adolescents with a range of disabilities and support to the families of these patients;
- National and international leadership and extensive research into child disability, particularly cerebral palsy, its causes and treatment;
- Teaching and collaboration with medical and allied health colleagues in clinical care and research. In particular, she places great importance on providing the best possible environment and support for young researchers to produce superior work;
- Administration of her hospital department, including staff and financial management, and securing funding for research;
- Active involvement in community organisations concerned with the welfare of people who are disabled or disadvantaged.

Professor Reddihough received the Royal Children’s Hospital Gold Medal in 2000 for her outstanding contribution to children with a physical disability and their families over so many years.”

APPENDIX 4: COMBINED STAFF AS AT JUNE 2006

The staff of Solve! and the Department of Child Development and Rehabilitation are composed of

- employees of the RCH and
- employees of the MCRI.

MCRI employees are involved only in research and rely on fund raising, that is grants from foundations, trusts and other competitive opportunities such as NHMRC, for their ongoing employment.

RCH employees do clinical work and many are involved in research for some part of their time, or contribute to research by assisting in recruiting patients and/or attending research meetings.

MRCI Staff

Ms. Anna Lanigan – 4 days

Ms Anne Marie McVeigh-Dowd – 1 day

Ms. Sue Reid – full time

Dr. Anne Rickards – part time dependent on needs of project

Mrs. Janet Walstab – 2 days

Ms Christine Westbury – 2 days

RCH Staff-Medical

Dr. Gordon Baikie

(5 Sessions)

Dr. Enver Bajraszewski

(1 Session)

Dr. Bronwyn Cathels

(1 Session)

Dr. Kevin Collins

(3 Sessions)

Dr. Kevin Dunne

(2 Sessions)

Dr. Catherine Marraffa

(4 Sessions)

Dr. Christine Olesch

(3 Sessions)

Associate Professor Dinah Reddihough

(full time)

Dr. Margaret Rowell

(2 Sessions)

Dr Giuliana Antolovich

(3 sessions)

RCH Staff-Nursing

Ms. Bev Touzel

(3 days)

Ms Katie Hazard
(3 days)
Ms Judy Wells
(4 days)
Ms Stella Dohle
(full time)

Secretarial

Ms Elizabeth Cassidy
(Full Time)
Ms Renate Ferns
(Part time)
Ms Sarah Anthony
(Part time)

Uncle Bobs Child Development Centre

Mrs. Michèle Spreckley – Manager and Physiotherapist
(Full Time)
Ms Tracey Earith – Teacher
(Full Time)
Ms Emma Witham – Teacher
(Part Time)
Ms Jacquie Simpson – Teacher
(Full Time)
Mrs Marilyn Brady – Assistant and Administration Assistant
(Part Time)
Ms Janice Minas – Assistant
(Part Time)
Ms Maria Rasquinka – Assistant
(Part Time)
Ms Trudy van Meggelen - Speech Pathology
(Part Time)
Ms Ruth Nevay – Speech Pathology
(Part Time)
Mrs. Jenny Tuck - Occupational Therapy
(Part Time)
Mr Kerry Fernando – Occupational Therapy
(Part Time)
Ms Sarah Rogers – Occupational Therapy
(Part Time)
Ms. Margi Richardson – Psychologist
(Part Time)
Ms. Margaret Charlton-Psychologist
(Part Time)

In addition, there are a number of students that undertake projects, ranging from medical students who spend 12 months in the department as part of their undergraduate degree, through to PhD students, to paediatric registrars who undertake projects as part of their

paediatric training program. All these students receive substantial support from the staff, particularly the research staff, who assist with project design and statistical analysis.

APPENDIX 5: SOLVE! AT THE RCH-ADVISORY PANEL MEMBERS

Bruce Bonyhady (Chairman)

Bruce Bonyhady is a Non-Executive Director. Two of his children have disabilities.

He is Chairman of ANZ Executors and Trustee Company Limited, Chairman of Acadian Asset Management Australia Limited and Chairman of the Investment Committee for the Deutsche Wholesale Property Fund.

He is also Chairman of the Yooralla Society of Victoria Limited and a Director of the Disability Housing Trust, which provides innovative housing solutions for people with disabilities in Victoria.

He is a Trustee of the William Buckland Foundation, a Member of the Felton Bequests' Committee and a Member of the Council of Philanthropy Australia.

Ms Anne Cronin

Anne Cronin is the Director of Finance and Operations at the Murdoch Childrens Research Institute and has responsibility for the Institute's Corporate and Technical Services.

Anne has a background as a medical scientist, before moving into management at the time of the establishment of the Murdoch Research Institute, 20 years ago. She is a Fellow of the Society of CPAs and of the Australian Institute of Management.

Anne is also a Director of University College at the University of Melbourne, Women's Health Victoria and the Australasian Research Management Society.

Dr D Robert Dickens

Robert Dickens is an Honourary Orthopaedic Surgeon and Consultant to the Department of Orthopaedics at the Royal Children's Hospital.

He was previously the Head of the Department of Orthopaedics at the Royal Children's Hospital and worked for many years with Associate Professor Reddihough and the Department of Child Development and Rehabilitation, to assist children with disabilities.

Mrs Anne McGeary

Anne McGeary has been raising funds for the Royal Children's Hospital since 1994. She was a founding member of Ultimate Challenge Auxiliary, which was established to raise funds for the Department of Child Development and Rehabilitation. 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 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 QLD, 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 at 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 3 years as President.

Associate Professor Dinah Reddihough, AO

Dinah Reddihough has been Director of Child Development and Rehabilitation at the Royal Children's Hospital since 1986. As well as leading the Department, Dinah is personally 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.

Dinah has been awarded 53 research grants and the outcome to date has been the publication of 72 journal articles and nine book chapters.

Other community involvement has included Medical Adviser to the Australian Cerebral Palsy Association since 1994 and to the Arthur Marsden Whiting Sympathy Fund since 1995. She has chaired the Scientific sub-committee of the Apex Foundation since 1998 and has been on the Board of the Yooralla Society since 1986. She was on the Wesley Mission Board of Management between 1989-2001, and has been Chair of the Wesley Church Council, Melbourne, since 2001.

Dinah launched the Australasian Academy of Cerebral Palsy and Developmental Medicine in 2001. This is a multidisciplinary group committed to advancing knowledge and awareness of the field of physical disability in childhood by conducting scientific meetings, promoting educational activities and fostering research and evidence based practice. She remains Chair of this organization which is now hosting conferences at two yearly intervals with workshops and other activities in the intervening periods.

Ms Judy Sproats

Judy Sproats is the Fundraising and Development Manager with The Royal Children's Hospital Foundation.

Judy is a Certified Fundraising Executive (CFRE) with 28 years experience of fundraising in the not-for-profit sector in the United States, Japan and Australia.

Mrs Doris Tatman

Doris Tatman was a secondary teacher for over 30 years and holds a Bachelor of Arts and Diploma of Education from Melbourne University. Her teaching experiences were both in the country and at Blackburn high School for 30 years.

She is the Immediate Past President and is currently Vice President of the Waverley Auxiliary of the RCH, which has been raising much needed funds for the Department of Child Development and Rehabilitation for many years.

APPENDIX 6: FINANCIAL FORECASTS 2006 TO 2010

	2006	2007	2008	2009	2010
Income					
Funding for Chair Paediatric					
Developmental Disability(a)	\$0.00	\$0.00	\$250,000.00	\$256,000.00	\$263,000.00
University funding of support for					
Chair of Paediatric DD(b)	\$0.00	\$0.00	\$50,000.00	\$51,000.00	\$53,000.00
Royal Children's Hospital ©	\$10,000.00	\$100,000.00	\$190,000.00	\$195,000.00	\$200,000.00
MCRI(d)	\$0.00	\$20,000.00	\$30,000.00	\$40,000.00	\$50,000.00
NH&MRC and other competitive					
research grants(e)	\$20,000.00	\$20,000.00	\$80,000.00	\$100,000.00	\$200,000.00
Recurrent CP Register funding		\$10,000.00	\$20,000.00	\$20,000.00	\$20,000.00
Trusts and Foundations(f)	\$60,000.00	\$80,000.00	\$100,000.00	\$90,000.00	\$100,000.00
Corporate Partnerships(g)	\$17,500.00	\$35,000.00	\$70,000.00	\$72,000.00	\$74,000.00
Auxiliaries	\$50,000.00	\$30,000.00	\$35,000.00	\$40,000.00	\$40,000.00
Individual donations & bequests	\$40,000.00	\$30,000.00	\$30,000.00	\$40,000.00	\$50,000.00
Annual fund raising events	\$10,000.00	\$12,500.00	\$15,000.00	\$17,500.00	\$20,000.00
Total Income	\$207,500.00	\$337,500.00	\$870,000.00	\$921,500.00	\$1,070,000.00
Expenditure					
Chair of Paediatric DD and					
research assistant	\$0.00	\$0.00	\$250,000.00	\$256,000.00	\$263,000.00
Salaries for research personnel	\$200,000.00	\$210,000.00	\$250,000.00	\$280,000.00	\$350,000.00
Other research staff -					
undergraduate/postgraduate(h)	\$10,000.00	\$50,000.00	\$170,000.00	\$250,000.00	\$250,000.00
Medical Staff Time(i)	\$0.00	\$0.00	\$90,000.00	\$92,500.00	\$95,000.00
Secretarial/Administration					
support	\$10,000.00	\$10,000.00	\$60,000.00	\$61,000.00	\$62,000.00
Consumables	\$5,000.00	\$7,500.00	\$10,000.00	\$15,000.00	\$20,000.00
Total Expenditure	\$225,000.00	\$277,500.00	\$830,000.00	\$954,500.00	\$1,040,000.00

Notes

- (a) Professorial salary of \$200,000 (indexed) plus research assistant costs of \$50,000 (indexed)
- (b) Secretarial and administration support for the Chair of Paediatric Developmental Disability
- © Payment of the research component of the salary of Associate Professor Reddihough and other research support
- (d) Murdoch Childrens Research Institute research grants
- (e) Competitive grant success is expected to jump sharply as Associate Professor Reddihough increases her research time and following appointment of the Chair of Paediatric DD
- (f) Based on current track record with trusts and foundations plus more strategic grants
- (g) Includes VMIA sponsorship
- (h) The cost of an undergraduate medical student is \$4,000 per annum and \$80,000 for a research fellow/post-graduate
- (i) Clinical costs of the Chair of Paediatric Developmental Disability

