THANK YOU
We thank the children who featured in this report:
Chloe, Jack, Jamie, Jordan, Lachlan, Logan and Sidhant.

Thank you also to the staff of the Kids Research Institute who helped with the report: Oliver Birke, Joshua Burns, Jonathan Craig, Russell Dale, Kim Donaghue, Min Hu, Michael Kohn, Robyn Jamieson, Loretta Lau, Geoff McCowage, Peter McIntyre, Kim Ramjan, Paul Robinson, Aaron Schindeler, Kate Steinbeck, Peter van Asperen, Val Wilson and Yvonne Zurynski.

Thank you to Amelia Hill and Karyn Joyner of the Research Office.

CONTENT
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Alice Pennington Design Pty Ltd

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Paul De Sensi and istock photo

PRINTING AND BINDING
St George Printers and Graphics
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Respiratory Medicine Research Group
SIDS and Sleep Apnoea Research Group
Department of Adolescent Medicine
Kids Rehab
Kids Heart Research
Kids Critical Care Research Unit
Emergency Department
Department of Anaesthesia
Department of Nuclear Medicine
Centre for Trauma Care, Prevention, Education and Research
Nursing Research and Practice Development Unit
The Centre for Evidence Based Paediatrics Gastroenterology and Nutrition
Children’s Hospital at Westmead Clinical School: Discipline of Paediatrics & Child Health

Research and support staff
Grants
Publications
Our supporters
Annual Report 2009-2010

Clinical Associate Professor Chris Cowell, Director, Kids Research Institute

It has been a busy year for the Kids Research Institute (KRI). After the completion of a major review of the organisation to improve our corporate and research governance, we have seen an increase in research performance; the recognition of a number of researchers and research students; involvement in the planning of new high platform research facilities for the Westmead Research Hub, and the improvement in the provision of research services.

Research is an integral part of our quest to improve child health here at The Children’s Hospital at Westmead, where all research conducted at the hospital falls under the research profile of KRI.

Now in our second year, the Kids Research Institute has become one of Australia’s leading paediatric health and medical research institutes. Our central aim is to be a world-class centre for clinical translational research in children.

Research excellence underpins everything we do at The Children’s Hospital at Westmead - it enhances our understanding of the basis of childhood disease, it enables us to prevent and cure disease, and it means we base our treatment decisions on evidence. It is only with a foundation of solid research that we can succeed in improving health outcomes for children in NSW and beyond.

Many of our researchers are also clinicians and base their research activities on the problems they encounter every day with their patients. But we also pride ourselves on our excellence in basic and population health research. This year we have received over $14 million in grants, a 10 per cent growth year on year, and published more than 350 papers.

A significant achievement in the last few months has been that a key research group within KRI, the National Centre for Immunisation Research and Surveillance of Vaccine Preventable Diseases (NCIRS), secured $15.61 million from the Commonwealth for the period 2010 to 2014. This will enable NCIRS to continue to support the objectives of the Immunise Australia Program in the areas of policy development, surveillance of vaccine-preventable diseases, program evaluation and professional communication and education.

Equally important has been the efforts that researchers and research staff have applied to building KRI’s profile locally, nationally and internationally.

Many of the staff who conduct research at KRI are leaders in their field. This year, I am proud to announce that a number of them have been recognised for their outstanding achievements.

Professor John Christodoulou, Head of the Genetic Metabolic Disorders Research Unit, was awarded an Order of Australia as a researcher and clinician in the field of human genetics.

Professor Louise Baur was awarded an Order of Australia in recognition of her outstanding commitment to understanding and tackling childhood obesity, poor nutrition and physical inactivity. She was also appointed the inaugural Theme Leader of Obesity and Metabolism as part of the Sydney Medical School’s Strategic Research Plan.

Associate Professor Cheryl Jones was awarded the 2009 Sydney Medical School Excellence in Higher Degree Research Supervision Prize and was appointed the inaugural Theme Leader of Reproductive, Maternal and Child Health as part of the Sydney Medical School’s Strategic Research Plan.

Professor Jonathan Craig was awarded The National Kidney Foundation’s 2010 International Distinguished Medal in the United States for his outstanding contribution to the study of kidney disease in children and adults.

Associate Professor David Little, Head of the Orthopaedic Research and Biotechnology Unit, was awarded the 2011 John Mitchell Crouch Scholarship and the Australian Orthopaedics Associate’s award for his contribution to international orthopaedic research.

PhD student Charmaine Tam presented her research...
into childhood obesity at the 60th Interdisciplinary Meeting of Nobel Laureates in Germany.

Operationally, staff from the Research Office are committed to providing high level support to our research community to enable research productivity and excellence. We have been fortunate to have Karyn Joyner join us this year as our Research and Development Manager. Her background in university and pharmaceutical industry management is already paying dividends.

One of the activities which KRI supports is the Hospital’s Human Research Ethics Committee (HREC). The HREC has recently been recognised through the award of a three-year national accreditation from the National Health & Medical Research Council’s (NHMRC) Quality and Regulation Branch to conduct ethical review processes for multi-centre research in children. The committee reviews more than 100 applications to conduct ethical research and more than 20 clinical trial applications each year.

With our focus on becoming a leading clinical translational research centre for children, it has been exciting to see KRI researchers and research students continue to build strong research linkages and collaborations with other medical research institutes, hospitals, universities, trusts and foundations and major donors. These include the Murdoch Children’s Research Institute, the Kolling Research Institute, the Centre for Eye Research, the Walter and Eliza Hall Institute, the Cancer Institute NSW, Canberra and Westmead Hospitals, Mount Sinai Hospital (Toronto), Ormond Street Hospital (London) and many of the top-tiered Australian Universities, including our primary tertiary partner, the University of Sydney.

Locally, KRI has led the Westmead Hub Partners in securing more than $1 million to fund the purchase and installation of the Correlative Light and Electron Microscopy suite. Funding sources include the Perpetual Foundation, Sydney Medical School Research Infrastructure Scheme 2009, the University of Sydney, Ian Potter Foundation, the Estate of the Late Valerie Street and the Cancer Institute NSW. Under the leadership of Professor Ian Alexander, cell-based therapies within the Westmead Research Hub have secured federal and state infrastructure funding. This will enable the development of gene therapy within KRI for children with rare, life-threatening diseases.

Future directions

This year, I have been formally appointed Director of KRI. I am excited about the opportunity to lead our vibrant research community and am committed to strengthening our research excellence and our national and international profile.

I am pleased to see the growth of our research groups and the establishment of new research groups including the Kids Critical Care Research Unit, which has been formed to conduct research into life-threatening illnesses in babies and children, and Emergency Medicine Research, which focuses on acute paediatric care. We are also very pleased to welcome Professor Kate Steinbeck as Medical Foundation Chair of Adolescent Medicine at the University of Sydney. Her appointment will integrate current research and build the evidence base needed to inform clinical practice for the treatment of adolescents.

The establishment of the Sydney Children’s Hospitals Network (Randwick and Westmead), the result of a recent merger of The Children’s Hospital at Westmead and Sydney Children’s Hospital, opens exciting possibilities for KRI. The Sydney Children’s Hospitals Network will be the largest paediatric hospital in Australia and this offers an incredible opportunity for clinical translational research.

I am extremely grateful to our outgoing Chief Executive, Dr Tony Penna, for his commitment to research and untiring support to develop KRI’s reputation as a leading clinical translational research centre for children. Dr Penna placed research next to clinical care, advocacy and education as a critical pillar of our mission to treat sick children. I welcome our new Chief Executive, Ms Elizabeth Koff, and look forward to developing with her the exciting opportunities for research ahead.

Our future challenges are to secure a sustainable income to support our infrastructure, to continue to achieve corporate and research governance improvements, and to provide essential research services for our laboratory-based, clinical and population health researchers. Our key funding priorities are to develop an integrated clinical trials centre that will provide a state-of-the-art facility for clinical translational research, and to enhance our laboratory-based research facilities to allow for growth of this key component of our research.

I wish to acknowledge the many supporters of KRI – their generosity is allowing us to achieve our vision of being a world-leading clinical translation research institute that will improve the health and lives of children.
Our organisation

Our Vision
To be a global leading translational research centre for children

Our Mission
To improve health outcomes and drive excellence in child health by:
- Discovering new insights into how diseases work, diagnostic methods and treatments
- Translating research outcomes into clinical practice within the Hospital and community
- Finding which potential treatments are effective and safe via the Australian Children’s Clinical Trials Centre
- Working collaboratively locally, nationally and internationally to improve child health

About the Kids Research Institute
The Kids Research Institute (KRI) is a leading paediatric health and medical research institute located at The Children’s Hospital at Westmead, near Parramatta in Sydney.

- KRI is the research arm of the Hospital and is responsible for its governance and management of research.
- KRI was launched in February 2009 to provide a sustainable destination for world-leading translational research in children. We now have more than 260 research and support staff, for many of whom research imperatives are driven by their clinical work in the Hospital.
- Our primary stakeholder is the University of Sydney and we are a key member of the Westmead Research Hub, the largest medical research precinct in NSW.

Our researchers are committed to finding ways to improve child’s health through:
- Basic science: Understanding the way diseases develop in children
- Clinical Research: Developing better diagnostic techniques and treatment methods
- Population Health Research: Understanding the impact of disease across the broader population.

We place a major emphasis on creating a research environment that enables world-class paediatric research. This includes conducting paediatric clinical trials to test the safety and efficacy of drugs and therapies especially designed for children and to translate laboratory findings into new clinical practices as quickly as possible.

Research areas are broad ranging and comprise of eight streams: Neurosciences and Mental Health; Tissue Engineering and Bone Repair; Cancer Biology; Genetics, Gene Therapy and Genomics; Obesity, Metabolism and Nutrition; Renal Medicine and Transplantation; Infectious Diseases and Immunology, and Clinical Services and Health Services Delivery.

Researchers are encouraged to collaborate to provide a multidisciplinary approach to improving child health. Our key collaborative partners are the University of Sydney, the Children’s Medical Research Institute and Westmead Millennium Institute, as well as many other prestigious institutions in Australia and overseas.
Research Council

Chair
John Dunlop AM

Secretary
Karyn Joyner

Members
Mr Daniel Petre AO
Prof David Handelsman
Dr Antonio Penna
Wendy Haigh

Ex-officio
A/Prof Chris Cowell
Prof Ian Alexander
Prof Kathryn North
Prof Peter McIntyre

Research Executive

Chair
A/Prof Chris Cowell

Secretary
Amelia Hill (to October 2009)
Karyn Joyner (from November 2009)

Members
Prof Ian Alexander
Prof Kathryn North
Prof Peter McIntyre
A/Prof Cheryl Jones
Dr Leanne Mills (to December 2009)

Human Research Ethics Committee

Chair
Margaret Kelly

Secretary
Karen Steinhoff (appointed February 2010)
Eleanor Thackray (mat. leave from February 2010)

Minutes Secretary
Jessica Moller

Laypeople
Ruth Burleigh
Matthew Campbell

Chief Executive's Representative
Dr Stuart Dorney

Lawyers
Ian Butcher MBBS LLB
The Hon. James Wood

Minister of Religion
Sr Patricia Bolster

Professional Care Member
Dr Peter Cooper (Deputy Chair)

External Researcher
Helen Slatyer (as of April 2010)
Dr Catherine McMahon (mat. leave from April 2010)

Basic/Laboratory Research
Dr Bruce Bennett
Dr Nicole Graf MBBS (Hons) FRCPA

Anaesthetic/Surgical Research
Dr John Harvey

Oncology Advisor
Dr Luce Dalla-Pozza (attendance for COG protocols only)

Clinical Trials Pharmacist
Pathma Joseph

Scientific Advisory Committee

Chair
A/Prof Chris Cowell

Secretary
Karen Steinhoff (appointed February 2010)
Eleanor Thackray (mat. leave from February 2010)

Minutes Secretary
Jessica Moller

Members
Margaret Kelly (HREC Chair - observer)
Dr Melanie Wong
Dr Gabrielle Williams
Prof Val Wilson
Dr Patrina Caldwell
Dr Belinda Barton
Dr Luce Dalla-Pozza
Dr Hiran Selvadurai
Pathma Joseph
Dr Nick Wood
Prof Robert Booy
Dr Davinder Singh
Dr Federica Barzi (mat. leave as of April 2010)
Liz Barnes (appointed April 2010)
Dr Sarah Garnett (appointed March 2010)
Dr Angie Morrow (appointed May 2010)

Radiation Safety reviewer
Yvette Wilson

Intellectual Property Committee

Chair
Dr Antonio Penna

Secretary
Amelia Hill (to October 2009)
Karyn Joyner (from November 2009)

Members
Wendy Haigh
A/Prof Chris Cowell
A/Prof David Little
Prof Ian Alexander
Dr James McCauley
Prof Valerie Wilson
Dr Wendy Hu (to March 2010)
Jackie Brooker (from June 2010)
Our facilities

The Australian Children's Clinical Trials Centre (ACCTC)

Established in 2008, the Australian Children's Clinical Trials (ACCT) Centre is one of only a few paediatric clinical trials centres operating across Australia and the first in NSW. It enables the many clinical trials conducted by research staff at the Kids Research Institute at The Children’s Hospital at Westmead every year.

The ACCT Centre serves all clinical investigators and industry partners who undertake clinical trials. It offers a range of services including development of protocols, assistance with funding and regulatory approval applications, biostatistical support, in-house training and templates to assist in running clinical trials.

Although children differ developmentally, physiologically and psychologically from adults, there has been surprisingly little research worldwide into what works specifically in children. Currently up to 80 per cent of drugs are not proven to be safe and effective for children.

Clinical investigators who work and conduct research at the Hospital have access to a large paediatric population, comprising the sickest children and the most complicated medical conditions. They are therefore well-placed to conduct important clinical trials that will determine what is safe and what works effectively for paediatric patients.

Some of the many international, national and local trials currently underway with the assistance of the ACCT Centre relate to childhood cancer, neuromuscular disease, eating disorders, obesity and diabetes, infectious disease, genetic metabolic disorders and kidney disease.

Westfield Gene and Cell Medicine Facility

The Westfield Gene and Cell Medicine Facility, completed in 2007 and recently expanded, is Australia’s first facility with an established capacity to manufacture clinical grade vectors for use in gene therapy trials. Vectors are cutting-edge gene delivery technologies derived from viruses. During gene therapy, isolated cells are genetically repaired in the laboratory and returned to the body via vectors.

The facility consists of two clean-room tissue culture laboratories and a clean contained laboratory linked to the central workroom by airlocks. Air quality is tightly controlled and maintained to Good Manufacturing Practice standards.

Paediatric Gait Analysis Laboratory

We are currently establishing the Paediatric Gait Analysis Service of NSW. Based at The Children’s Hospital at Westmead, it will offer a state-wide service analysing the gait of children with cerebral palsy who require complex orthopaedic surgery.

The evaluations conducted by this service will take place in the Paediatric Gait Analysis Laboratory, located within the Kids Research Institute (KRI). This facility has been established by refurbishing the KRI Human Movement Research Laboratory. It includes the most cutting-edge equipment, ensuring NSW is a leader in this field.

In a system similar to that used by Hollywood animators, eight cameras positioned around the laboratory pick up sensors attached to patients as they walk. With three cameras always able to view a sensor at any one time, three dimensional images are captured of how patients’ limbs and muscles are functioning. Force plates embedded within the floor of the laboratory measure how much force patients use as they touch the ground, enabling diagnosis of walking problems.

Gait analysis allows a precise tailoring of surgery to the needs of the individual child and gives surgeons the confidence to undertake Single-Event Multi-Level Surgery (SEMLS), which aims to combine all relevant procedures into a single episode of surgery. Previously, children with cerebral palsy routinely underwent multiple surgeries to improve their ability to walk. Initially catering to children with cerebral palsy, this technology also has potential to optimise the treatment of children with muscular dystrophy, Charcot-Marie-Tooth Disease and other disabilities.
Cell Imaging Suite

The Cell Imaging Suite enables researchers to view how disease processes work at a cellular level. The suite of instruments provides transmitted, fluorescence and confocal microscopy and live-cell imaging and laser capture microdissection microscopy, which assist in viewing and analysis of objects in the body thousands of times smaller than one millimetre. The suite also provides specialised software that enables researchers to analyse their data. During the last 18 months, more than $1 million has been raised in grants and donations to purchase a new confocal microscope and portable high pressure freezer (Correlative Light and Electron Microscopy Suite) that will enable researchers to look at living cells using fluorescence, snap freeze their samples, and then view them in even greater detail using the electron microscopes at the Transmission Electron Microscopy Laboratory at Westmead Hospital.

This will give our researchers at KRI the unique ability to identify cells in action and then view the molecular components of the structures that are causing the action to happen. This helps them understand the basis of childhood diseases.

Tissue Bio-banks

The Tumour Bank stores human tissue for research into the causes and treatment of childhood cancers. The Tumour Bank holds more than 25,000 specimens collected from nearly 3,000 patients with cancer, representing over 50 types and sub types of malignancy.

The collection includes solid tumours specimens, whole blood, bone marrow (both whole and dried onto slides), and serial leukaemia specimens as well as cerebral spinal fluid and plasma samples. A database maintains a record of each sample in the collection, along with basic clinical data pertaining to the specimen. Patients are never identified.

The Children’s Hospital at Westmead's Tumour Bank is a founding member of the Australasian Biospecimens Network (ABN). ABN-Oncology is a national network of biobanks established to collect, process and disseminate biospecimens for research, ranging from basic laboratory projects through to clinical trials. The network leverages off collection of relatively common tumour types, including colorectal and breast cancer, and strategically targets specific tumour types such as mesothelioma and rare paediatric tumours that can only be collected in substantial numbers through the formation of such a network. The ABN has significant links with other international organisations including International Society for Biological and Environmental Repositories (ISBER), UK Biobank, Swedish National Biobank Program and Tubafrost (EU).

Other Tissue/Bio-banks have been established from children with cardiac, neuromuscular and kidney disease by researchers at KRI. In collaboration with national and international researchers, specimens from these tissue bio-banks have helped to identify some of the causes of childhood disease which, in turn, will hopefully lead to new treatments.
John Dunlop AM
Mr Dunlop became a member of the board of The Children’s Hospital at Westmead in 1973 and served as President from 1983 to 2005. He has also been Honorary Treasurer (1978 - 1981) and Vice President (1981 - 1983). He is an external member of a number of the Hospital’s committees, a Director of the Children’s Medical Research Institute, and is Chairman of the Hospitals’ Contribution Fund of Australia Limited. Formerly Managing Director of Edwards, Dunlop & Company Limited, Mr Dunlop was a Director of Health Super Pty Ltd and Health Super Financial Services Pty Ltd between 2000 and 2007. In 1987, Mr Dunlop was appointed a Member of the Order of Australia in recognition of his work for child health.

Daniel Petre AO
Mr Petre has been at the forefront of the technology industry in Australia for more than 20 years. Prior to founding the technology investment company Netus, he spent nine years at Microsoft, including three years as Managing Director, Australia. He went on to found Ecorp, a subsidiary of Publishing and Broadcasting Limited (PBL), which became Australia’s leading internet company. Mr Petre has made an extensive contribution to the not-for-profit sector, with positions held on the Area Health Advisory Council for The Children’s Hospital at Westmead, the Advisory Board of HealthInsite and The UNSW Foundation, among many others. Mr Petre and wife Carolyn set up the Petre Foundation in 2000, which has funded research chairs both at The Children’s Hospital at Westmead and the Garvan Institute, as well as a scholarship for university medallists at UNSW.

Professor David Handelsman
Professor Handelsman is Australia’s first Professor of Andrology (1996), inaugural Professor/Director, ANZAC Research Institute (1998), Head of the Andrology Department at Concord Hospital (1999) and Associate Dean (Research Strategy), Sydney Medical School. He has served on numerous research and health policy advisory bodies. He was awarded the RACP Susman Prize (1994), the inaugural AMA Men’s Health Award (2003) and Honorary Life Member, Endocrine Society of Australia (2008). Over 30 years he has published over 360 scientific papers while maintaining continuous funding from peer-reviewed and industry grants. He has served on the editorial boards of 15 journals, been an invited reviewer for 103 peer-reviewed scientific journals and contributed to NHMRC peer-review for over 20 years serving on all types of grant and fellowship committees.

Dr Antonio Penna
Dr Penna was appointed to the position of Chief Executive of The Children’s Hospital at Westmead following Prof Kim Oates’ retirement in 2006. For one year prior to this he was Director of Clinical Services – Medical. Before joining The Children’s Hospital at Westmead, Dr Penna was the Director of Medical Services at Royal North Shore Hospital, a position held since 1997. He completed his paediatric training at the Adelaide Children’s Hospital and was an NHMRC Postgraduate Fellow at the University of Melbourne, where he completed his doctorate in pharmacokinetics. In 1992, he became Clinical Superintendent in the Department of Paediatrics at Westmead Hospital, where he was subsequently promoted through a range of administration positions while maintaining a clinical role. Dr Penna’s role on the Council and as Chief Executive of The Children’s Hospital at Westmead, ceased on 30 June 2010, when the Hospital transitioned to the Sydney Children’s Hospitals Network (Randwick and Westmead). He is now Director of Local Hospital Networks at NSW Health.

Wendy Haigh
Ms Haigh joined The Children’s Hospital at Westmead in August 2006 as Director of Finance and was appointed Director of Finance and Corporate Services in May 2007. She has a successful track record in finance, having held a number of senior management positions across both the private and public sectors. After completing an honours degree in accounting, Wendy qualified as a Chartered Accountant with PricewaterhouseCoopers in the UK before transferring to Sydney in 1984. She is a Fellow of the Institute of Chartered Accountants of England and Wales, an Associate of the Institute of Chartered Accountants of Australia, and a member of the Australian Institute of Company Directors.
Associate Professor Chris Cowell
Associate Professor Chris Cowell is Director of the Kids Research Institute and is a Senior Staff Specialist in the Institute of Endocrinology and Diabetes at The Children's Hospital at Westmead. He has been Director of Clinical Research at the Hospital since 2005, a part-time position created to help advocate and develop clinical research and its infrastructure. A Clinical Associate Professor of the University of Sydney, Associate Professor Cowell trained as a paediatric endocrinologist in Toronto and Sydney and has extensive clinical experience in diabetes, growth, obesity-related metabolic syndrome and disorders of bone metabolism. His major research interests are the prevention of metabolic complications of obesity in teenagers and the effects of disease states on bone mass and bone geometry.

Professor Ian Alexander
Professor Alexander is a clinician scientist involved in both patient care and biomedical research. He is a senior staff specialist in genetic metabolic disease and Director of Laboratory Research in the Kids Research Institute and also heads the Gene Therapy Research Unit. A recognised pioneer of gene therapy in Australia, Professor Alexander’s specific expertise and interests include virus-mediated gene transfer with a focus on target organs, including the liver and bone marrow. He was elected inaugural president of the Australasian Gene Therapy Society (ASGT) in 2001, appointed Chair of the National Health and Medical Research Council’s Cellular Therapies Advisory Committee in 2007, and awarded life membership of the ASGT for services to the field in 2009. He is an Associate Editor of the Journal of Gene Medicine and member of the Editorial Boards of Current Gene Therapy and Human Gene Therapy.

Professor Kathryn North
Professor North is the Douglas Burrows Professor of Paediatrics and Associate Dean of The Children’s Hospital at Westmead Clinical School, within the Faculty of Medicine at The University of Sydney. Trained as a paediatric physician, neurologist and clinical geneticist, she completed a postdoctoral fellowship at Harvard Medical School before returning to Australia in 1995 as the recipient of The Children’s Hospital Research Career Development Award. At The Children’s Hospital at Westmead, Professor North runs the Neurogenetics Clinical Service and heads the Institute for Neuroscience and Muscle Research. Professor North leads a large multi-disciplinary team which cares for more than 1800 patients. Her research interests include the molecular basis of inherited muscle disorders, genes that influence skeletal muscle function, and new therapies for muscular dystrophy and neurofibromatosis type 1.

Professor Peter McIntyre
Professor McIntyre is the Director of the National Centre for Immunisation Research and Surveillance of Vaccine Preventable Diseases (NCIRS) and a Senior Staff Specialist in Infectious Diseases at The Children’s Hospital at Westmead. His major interests are in the epidemiology of vaccine preventable diseases, particularly invasive Haemophilus influenzae type b (Hib), pneumococcal disease and pertussis. He has been a member of the Australian Technical Advisory Group on Immunisation (ATAGI) for some years, and also sits on the Communicable Diseases Network of Australia (CDNA) and the National Immunisation Committee (NIC). Professor McIntyre is a reviewer for over 10 national and international journals, has been an invited speaker at a number of international and national meetings, and is the author of over 150 papers and book chapters.

Karyn Joyner
Ms Joyner is the Research and Development Manager at the Kids Research Institute. She is an experienced senior manager with more than 19 years experience in laboratory research, pharmaceutical sales and marketing, FMCG Scientific (R&D) management, international business and international regulatory disciplines and entrepreneurial investment, in addition to working within university environments supporting research and business development. This has included activities such as international collaborative research development, commercialisation of research outcomes and developing high performance teams.
Operating Statement for the year ended 30 June 2010 (unaudited)¹

<table>
<thead>
<tr>
<th></th>
<th>2009/10 $000's</th>
<th>2008/09 $000's</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Revenue from all sources</strong></td>
<td></td>
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</tr>
<tr>
<td>Research Grants</td>
<td>14,228</td>
<td>12,344</td>
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<tr>
<td>Donations and Other Contributions</td>
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<td>Infrastructure Support²</td>
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<td>Block Funding³</td>
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<tr>
<td>Investment Income</td>
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<td>432</td>
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<tr>
<td><strong>TOTAL REVENUE</strong></td>
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<td>24,574</td>
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<tr>
<td><strong>Expenditure on research operations</strong></td>
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<tr>
<td>Employee Related Expenditure</td>
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<td>13,459</td>
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<tr>
<td>Goods and Services</td>
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<tr>
<td>Repair, Maintenance, and Renewals</td>
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<td>465</td>
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<tr>
<td>Depreciation</td>
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<td>897</td>
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<tr>
<td><strong>TOTAL EXPENDITURE</strong></td>
<td>22,522</td>
<td>21,134</td>
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<tr>
<td><strong>RETAINED SURPLUS / (DEFICIT)</strong></td>
<td>1,381</td>
<td>3,440</td>
</tr>
</tbody>
</table>

**Resource Allocation ($000’s)**

- **Revenue**
  - 60% Research Grants $14,228
  - 22% Donations and Other Contributions $5,337
  - 10% Infrastructure Support $2,346
  - 4% Investment Income $984
  - 4% Block Funding $1,008

- **Expenditure**
  - 66% Employee Related Expenditure $14,766
  - 29% Goods and Services $6,561
  - 2% Repairs, Maintenance and Renewals $507
  - 3% Depreciation $688

**Notes**

1. Kids Research Institute is the research division of The Children’s Hospital at Westmead. Separate financial statements are not audited for the Kids Research Institute. The audited financial statements of The Children’s Hospital at Westmead are available on request or you can visit our website at www.chw.edu.au
2. Infrastructure support has been provided by The Children’s Hospital at Westmead.
3. Block funding has been provided by NSW Department of Health to the National Centre for Immunisation Research and Surveillance.
## Balance Sheet as at 30 June 2010 (unaudited)\(^1\)

<table>
<thead>
<tr>
<th></th>
<th>2009/10 $000's</th>
<th>2008/09 $000's</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Current Assets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cash at Bank and Investments</td>
<td>29,290</td>
<td>25,200</td>
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<tr>
<td><strong>Non-Current Assets</strong></td>
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</tr>
<tr>
<td>Investments</td>
<td>4,768</td>
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<tr>
<td>Buildings(^4)</td>
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<tr>
<td>Plant and Equipment</td>
<td>1,965</td>
<td>1,963</td>
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<tr>
<td><strong>NET ASSETS</strong></td>
<td><strong>53,743</strong></td>
<td><strong>52,361</strong></td>
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<tr>
<td><strong>Represented by</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accumulated Funds</td>
<td>52,105</td>
<td>48,664</td>
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<tr>
<td>Revaluation Reserve</td>
<td>257</td>
<td>257</td>
</tr>
<tr>
<td>Retained Surplus / (Deficit)</td>
<td><strong>1,381</strong></td>
<td><strong>3,440</strong></td>
</tr>
<tr>
<td><strong>RETAINED EQUITY</strong></td>
<td><strong>53,743</strong></td>
<td><strong>52,361</strong></td>
</tr>
</tbody>
</table>

### Resource Allocation ($000’s)

**Assets - FY 2009/10**

- **54% Current Cash and Investments** $29,290
- **33% Buildings** $17,720
- **4% Plant and Equipment** $1,965
- **9% Non-Current Investments** $4,768

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4. The main building of the Kids Research Institute is owned by The Children’s Hospital at Westmead. The estimated value of buildings recognised above is based on the floor space occupied by Kids Research Institute.
Smart Science, Healthy Future
Stream 1

Neurosciences and Mental Health

The Children’s Hospital at Westmead boasts some of Australia’s best clinicians and researchers in the area of neurosciences and mental health. Our research centres on the effect of the brain and muscles on child health and well-being.

This research endeavours to understand the causes and mechanisms of a range of disorders and diseases. Much of our work involves neurological diseases such as muscular dystrophy and neuromuscular disorders. We look for new genes that may explain why some children develop brain and muscle disorders and why dysfunction in particular genes or proteins causes symptoms.

All of our research aims to improve treatment for the children we see every day in our clinics. Our eating disorders research involves finding and testing the best treatment regime for the rapidly growing number of children presenting to our Hospital. We also aim to understand how the brain works in children with varying conditions from brain tumours to sleep disorders and dyslexia.

Institute for Neuroscience and Muscle Research (INMR)

Group Leader: Professor Kathryn North

Leaping ahead in muscle and nerve research

We research and treat brain, muscle and nerve disorders including muscular dystrophies, neurofibromatosis, multiple sclerosis and brain tumours. Our vision is to enhance the translation of basic research - like gene discovery, study of disease pathogenesis and development of novel therapeutic approaches - into improved patient care and quality health outcomes in a clinical setting.

Research

Our research focuses on three major areas: to identify the cause of these disorders and enable accurate diagnosis; to understand why dysfunction of a particular gene or protein results in weakness, and thus improve treatment, and to develop specific therapies and interventions that will overcome or alleviate physical disabilities.

Innovative therapies for muscular dystrophies, particularly Duchenne Muscular Dystrophy (DMD), are resulting in significant benefits for our patients. Access to these therapies has improved the lifespan by up to 15 years and the INMR Clinical Trials and Quality of Life Program will continue to deliver benefits to our patients. Our current clinical trials include exon skipping for DMD, a therapy that holds great promise, and a global trial of PTC124 (Ataluren), a novel compound that aims to directly correct the genetic defects in a subset of patients.
Understanding the mechanisms of **muscle function** in human health and disease has led us to new insights into a number of dystrophies, potentially improving clinical diagnosis and leading to the development of specific therapies. Our novel finding of a gene associated with human athletic performance has led us to the intriguing discovery that the gene is also linked to increased susceptibility to obesity and diabetes. In a world first, we led the first paediatric trial of ascorbic acid (Vitamin C) for **Charcot-Marie-Tooth Disease (CMT)** type 1A in Australia. Results of this study will contribute to international health policy and to improved clinical care of children with CMT type 1A.

We have established a **diagnostic service** for inherited myopathies and congenital and limb girdle muscular dystrophies, offering unequivocal diagnosis for more than 30 of 60 identified disorders. The subsequent development of a biospecimen bank has improved the clinical and molecular classifications of muscular dystrophies and has allowed us to better understand the pathogenic mechanisms underlying the disorders. This service is available free of charge to clinicians throughout Australia and South-East Asia.

We have identified an important autoimmune response against a protein in children with **acute brain demyelination**. This finding has potential implications for childhood and adult multiple sclerosis, and will hopefully define tailored therapy in the future.

We have established a Neurosurgery Research group studying potential therapies for hydrocephalus and brain tumours.

We are also leading clinical trials for children and adults with the inherited tumour disorders **neurofibromatosis types 1 and 2 (NF1 and NF2)**. The INMR is the lead institution in an international trial of Lovastatin for the treatment of cognitive deficits in NF1. We have recently initiated trials of two novel agents for the treatment of devastating tumours that affect vision and hearing in children and adults with neurofibromatosis.

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**Eating Disorder Service, Departments of Psychological Medicine and Adolescent Medicine**

**Group Leaders:** Dr Sloane Madden; Associate Professor Michael Kohn

**Innovative treatment of eating disorders**

The Hospital’s Eating Disorder Service is the largest child and adolescent eating disorder service in NSW. There has been a 270 per cent increase in inpatient numbers and a 1000 per cent increase in outpatient numbers since our establishment in 2000. To help us meet this demand, our research interests focus on how to optimise treatment. Our strong focus on clinical research drives innovation in the treatment of children and their families with this debilitating condition.

Over recent years, our research team has forged strong links with other treatment services and universities, including the Adolescent Eating Disorder Service at Westmead Hospital, the Departments of Gastroenterology and Endocrinology at The Children’s Hospital at Westmead, the Garvan Institute, the Departments of Psychology and Psychiatry at the University of Sydney, the University of Western Sydney, the Australian Paediatric Surveillance Unit, the Great Ormond St Hospital in London, the Hospital for Sick Children in Toronto and the University of Kiel in Germany.

**Research**

Our research focus is on driving innovation and finding the optimal way to treat eating disorders. Our current work includes an **NHMRC-funded inpatient trial** researching the impact of brief admissions for medical stabilisation versus current admission lengths. The final family will have completed the treatment protocol in October 2010 and the annual review of each family to five years will be completed in 2015. We aim to present initial findings at international scientific meetings and in peer-reviewed literature in 2011.

This year, a new randomised control trial was funded to investigate the impact of an enhanced form of cognitive behavioural therapy on anorexia nervosa patients. This enhanced **LEAP treatment** focuses on some features of anorexia nervosa that have been found to prevent people from recovering. This study has just commenced recruitment.

Ongoing research continues to investigate processes in family treatment in eating disorders, reasons for treatment withdrawal, early onset eating disorders in children under the age of 12, neuro-imaging in eating disorders, re-feeding and body composition, neurophysiology in eating disorders, and bone changes in eating disorders.

Our clinical research focus has inspired a number of clinical and community-based programs over the past year, including hosting our second national conference, presenting seminars to school counsellors, and running parent family groups. We have opened our first family treatment unit, the Butterfly Wing, which provides facilities for one to two week family admissions, where parents can learn how to refeed their child with intensive support from our multidisciplinary team.
Children’s Hospital Education Research Institute (CHERI)

**Group Leader:** Dr Belinda Barton

**Improving learning in sick children**

We work to achieve the best possible outcomes for children with medical, developmental or psychological conditions by improving the interface between health care and education. Our research efforts focus on establishing the cognitive and psychosocial profile of children with conditions such as neurofibromatosis type 1 (NF1), cancer and velocardiofacial syndrome.

**Research**

Our research centres on characterising the cognitive profile of children with a clinical condition who also have learning difficulties. For example, in conjunction with the Institute for Neuroscience and Muscle Research (INMR), we are currently involved in a randomised placebo-controlled study of **lovastatin in children with NF1** to see whether this medication can reverse learning difficulties. We are also following the development of children with NF1 from infancy to school age to identify those children at risk of poor academic performance. These projects are ongoing and will continue for a number of years.

We are studying health-related quality of life and social support in children newly diagnosed with cancer, as well as the vocational development of adolescents with cystic fibrosis. Our other research interests include everyday memory in children with idiopathic generalised epilepsy and the assessment of motor and cognitive abilities in children with acquired cerebellar disease.

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Developmental Cognitive Neuropsychology Research Unit (DeCog)

**Group Leaders:** Clinical Associate Professor Pam Joy, (to March 2010); Dr Ruth Brunsdon, (from March 2010).

**Understanding the neuropsychology of sick children**

The Developmental Cognitive Neuropsychology (DeCog) Research Unit is an internationally recognised developmental neuropsychology research facility. Using evidence-based treatment programs, we assess and treat children and adolescents who have reading and spelling disorders and help them to come to enjoy these activities. We continue to provide a high level of research, with plans to increase our focus on paediatric cognitive rehabilitation. We are at an early stage of establishing collaboration with the Hospital’s Rehabilitation Department.

This year has seen a significant shift within DeCog, with the retirement of both its founders, Clinical Associate Professor Pam Joy and Emeritus Professor Max Coltheart.

**Research**

In collaboration with a number of specialist departments at the Hospital, we are conducting a series of **Neuropsychological Outcome Studies**, which investigate neuropsychological outcomes and monitor neuropsychological status in children with developmental or acquired disorders. The information gleaned from these studies is likely to have a significant impact on medical and cognitive outcome in children with quite varying conditions. The clinical populations currently under investigation include children with acquired cerebellar disease, brain tumour, brain injuries, diabetes and sleep disorders.

Our **Cognitive Neuropsychological Studies** typically include case studies of children with disorders such as dyslexia, amnesia or face processing deficits. We use theoretical models to explain cognitive processes and to aid in our understanding of developmental disorders.

Our studies have a direct clinical application, and have resulted in new empirically validated methods for the assessment and treatment of cognitive disorders in children with developmental disorders as well as brain tumours and traumatic brain injuries.

“We assess and treat children and adolescents who have reading and spelling disorders and help them to come to enjoy these activities.”
Snapshot: Institute for Neuroscience and Muscle Research

“A teaspoon of liquid may be able to help Chloe and other kids with this serious condition.”
– Associate Professor Joshua Burns, Head of the Clinical Research Team, Institute for Neuroscience and Muscle Research

Chloe paves the way for turmeric drug breakthrough

Diagnosed at two with the rare and debilitating peripheral neuropathy Dejerine-Sottas Disease, teenager Chloe Liso has been confined to a wheelchair throughout high school. To make matters worse, in the last few years she has developed serious and frightening breathing problems.

At first, therapy meant she could walk and play like other children. But her condition deteriorated during Year 5 and she developed scoliosis of the spine, which required complicated surgery.

Her health problems continued through her teenage years, to the extent that she could no longer walk. Her lungs were also affected by the disease and for two consecutive years she spent weeks in hospital with pneumonia. She still uses a BiPAP machine to sleep at night.

“Chloe was on a downhill progression and things were getting really bad, really quickly,” says one of her doctors, Associate Professor Joshua Burns.

There were few remaining medical options. Then evidence emerged from the United States that curcumin, a compound derived from the curry spice tumeric which has long been used in traditional Indian medicine, could be helpful for patients with Dejerine-Sottas Disease.

Chloe and her parents were keen to try the treatment, and Associate Professor Joshua Burns agreed.

“Curcumin was something known to be safe, so we decided to make her a case study – to measure it properly and see if it made her disease slow down or made it better,” he says.

For two years Chloe took 10 capsules of curcumin every day, until recently a pharmaceutical company started to produce a new fast-acting curcumin, which means she can receive the same dose from just 10 ml of liquid.

While there is no evidence that the curcumin made a neurological difference to Chloe’s condition, she has not deteriorated further and has not been admitted to hospital since she started the medication. She has recently completed her HSC and is looking forward to a bright future – possibly as a medical researcher.

“For the last 10 years I have always received such quality care from the Institute for Neuroscience and Muscle Research, so I really believed that the team would only suggest a trial that they felt would benefit my wellbeing. It appears to have contributed to my improved health over the last two years and I am grateful to have been given this opportunity,” she says.

Associate Professor Burns is now planning a larger trial of curcumin in younger patients with Dejerine Sottas Disease.

“Chloe was well until about age 10, so there’s probably a window where we can do more with curcumin, if it’s going to work, before the children become weak and develop lung problems,” he says.
Staff profile:
Dr Russell Dale, Head, Neuroimmunology Group,
Institute for Neuroscience and Muscle Research (INMR)

Antibody finding promises complete recovery for children with encephalitis

Encephalitis lethargica is an enigmatic disease that has been described for centuries and causes abnormal sleep, behaviour, and movement disorders such as Parkinsonism. Its intriguing symptoms have captured the imagination for decades and it was featured in the film *The Awakenings*, starring Robin Williams, and the books by Oliver Sacks.

Encephalitis lethargica continues to occur, although thankfully not in epidemic forms as in the 1920s. Dr Russell Dale has been treating patients with this encephalitis for the last 10 years, and has proposed that it may be an autoimmune disorder, meaning the host immune system attacks the brain.

Autoimmune brain disorders are responsible for 10 per cent of all acute admissions to the neurological ward at The Children’s Hospital at Westmead. These autoimmune disorders occur when the body produces inappropriate antibodies, which attack the brain and cause neurological problems.

The Institute for Neuroscience and Muscle Research’s Neuroimmunology Group, headed by Dr Dale and his colleague Dr Fabienne Brilot-Turville, has shown that patients with encephalitis lethargica produce antibodies which attack an essential receptor in the brain, called NMDA-receptor.

The finding, published in the prestigious journal *Annals of Neurology* in 2009, means this form of autoimmune encephalitis can be diagnosed with a simple blood test and treated effectively.

The INMR houses one of only three laboratories in the world able to test for the antibodies associated with this form of encephalitis.

“Before we just hoped the patients would get better. But this gives us the ability to treat them aggressively with immune therapy and help them recover,” says Dr Dale.

Strong immunosuppressant therapy means most patients now walk out of hospital fully cured. There is about a 10 per cent relapse rate in the first year, but many of the children treated by Dr Dale are completely well five years later.

Before this finding doctors were able to accurately diagnose only about 30 per cent of encephalitis cases. “Not only will this finding improve diagnosis, but it suggests that we will be able to diagnose and treat other forms of encephalitis in the future.”
Our central aim is to find new and exciting ways of helping the body to heal itself. We study the healing process from the cells up, and work to develop better treatments for children who come to our hospital with injuries or conditions that affect their bones and tissue.

Our flagship research work is conducted in the area of orthopaedics and biotechnology – the study of bone diseases and bone repair. We are world pioneers in the use of medications that promote bone growth and inhibit the processes which stop bone from healing.

Our wound healing laboratory investigates what happens at a cellular level when wounds heal, especially after a burns injury. Our research has made great advances in promoting burns prevention and appropriate first aid in the community.

Orthopaedic Research and Biotechnology Unit (ORBU)

Group Leader: Associate Professor David Little

Fixing kids’ bones

The Orthopaedic Research and Biotechnology Unit aims to advance orthopaedic care through an improved understanding of bone diseases, bone healing and pharmaceutical therapies. Our high calibre team consists of orthopaedic surgeons, orthopaedic surgical fellows, research scientists and biomedical engineers.

Research

We have enjoyed significant academic and grant success, with 11 dedicated research staff now working on a wide range of translational projects. Of the more than $3.8 million we have received in grants in the last 10 years, two have supported clinical trials of projects which began in the laboratory.

Associate Professor Little pioneered the use of bisphosphonates in paediatric medicine and this work is now directly helping children within the Hospital. Our work in bisphosphonates has led to the development of one of our main research themes – optimisation of the anabolic (bone-forming) and catabolic (bone-resorbing) responses. We are currently achieving early success in combining local anabolic treatment with systemic bisphosphonate therapy.

We have developed models of the orthopaedic manifestations of Neurofibromatosis type 1 (NF1), a common genetic disease affecting one in 3,000 children that can manifest as a variety of characteristic symptoms including the formation of tumours. We have recently published studies looking at common orthopaedic conditions in these children, showing that dual problems in bone anabolism and bone catabolism may both contribute to the way NF1 affects bones.

We have developed new advanced genetic cell tracking models and have been able to show, for the first time, how muscle cells contribute to bone formation. This work has the potential to dramatically affect orthopaedic surgical practice and lead to new innovations in bone tissue engineering.
Other emerging research directions include the collection of bone samples from surgical patients, with and without genetic bone disease, for the use in future research projects. We are also testing several compounds for their efficacy in the treatment of orthopaedic complications. These drugs have the potential to revolutionise orthopaedic medicine. We have established surgical models and high-tech scanning, histology, and molecular outcomes for testing these drugs.

Children’s Hospital Burns Research Institute (CHBRI)

**Group Leaders:** Associate Professor Andrew Holland, Dr John Harvey, Dr Rachael Murray

**Helping burns and wounds to heal**

The Burns Unit at The Children’s Hospital at Westmead has long had a reputation for clinical excellence. In 2005 the Children’s Hospital Burns Research Institute (CHBRI) was established to build upon this strength in the area of laboratory-based burns research.

**Research**

Despite a dramatic increase in survival rates for children who are burnt, up to 35 per cent of patients who are hospitalised with a scald burn subsequently develop hypertrophic scars, which can result in functional impairment as they grow.

Professor Andrew Holland’s research has highlighted the role of a group of cells, called fibrocytes, in the development of hypertrophic scar tissue. This understanding may lead to the possibility of inhibiting fibrocyte formation and thus prevent scarring. Our group currently investigates the impact on the timing of skin grafting after burn injury on the severity of subsequent scarring. This knowledge will inform clinicians’ decisions regarding the optimal time to graft a deep dermal burn to minimise the risk of long-term scarring.

The CHBRI Wound Healing Laboratory was established in 2007 under the direction of Dr Rachael Murray to undertake research into the cellular and biochemical processes that occur in acute burns wounds and in the role of an inflammatory cell, called the macrophage, in the development of a burns scar.

Previous work in our laboratory with our burns wound model established the experimental basis for the effectiveness of cold running water as a first aid measure. This led to increased promotion publically of the importance of first aid in the initial treatment of acute burns to minimise the risk of long term scarring.
**Snapshot: Orthopaedic Research and Biotechnology Unit**

“Our research in Associate Professor David Little’s laboratory has achieved a marked improvement in the amount of bone formed in experiments using new methods to promote bone healing.” – Dr Oliver Birke, Postgraduate Fellow, Orthopaedic Research and Biotechnology Unit.

**Advanced technology helps Lachlan’s bones grow back**

A small lump on the left shin, discovered when Lachlan Giang was a toddler, could have been devastating.

He was diagnosed with Osteofibrous Dysplasia Campanacci, where part of the shin bone is replaced by fibrous tissue. If it had been left, Lachlan could have experienced fractures, progressive bowing of the leg and even the development of cancer.

Surgery was advised – a very difficult operation in which the bone would be completely removed and the resulting gap somehow filled with bone again. There was little option.

“As he got older, his growing weight might have caused his leg to bow even more and it would have been likely to fracture, and the rest of his joints would have been out of alignment,” says Lachlan’s mother, Vanessa.

Luckily for Lachlan and his family, advanced understanding of bone healing and treatment methods, developed by the Orthopaedic Research and Biotechnology Unit (ORBU), is helping him to grow back his own bone in the gap.

First surgeons removed the portion of tibia, where the fibrous lump was located. They then laid bone cement to temporarily fill the gap. This created a space lined by a membrane that could then be filled with bone a few months later. A frame was applied around the leg to support and stabilise it.

In a second operation, a portion of bone was taken from Lachlan’s own fibula and inserted into the gap together with small pieces of bone graft. This inserted bone and the two ends of the shin bone on either side of the gap then had to heal together to recreate a new, stable continuous shin bone.

To support the bone healing, bisphosphonate infusions were used. Bisphosphonates block the bone eating cells and leave the bone-building cells to do their work. In order to encourage the piece of fibula that had been removed to grow back, bone morphogenetic proteins (BMP, a special protein that induces bone healing) was used. Lachlan’s fibula grew back within six weeks.

While Lachlan’s treatment has been revolutionary, healing has still been slow and has required him to have the external frame fixed to his leg for several months. However, laboratory work being undertaken by the ORBU is aiming to further improve the treatment of this kind of condition.
These days it is possible to grow bone in children. At our Hospital, advanced surgical techniques are being combined with new drug therapies that produce and retain large amounts of new bone to promote healing after a traumatic injury or tumour resection.

But while doctors know what works clinically, little is understood about what is happening at a cellular level as the new bone grows. Research Scientist Dr Aaron Schindeler spends his days tracking cells to find out.

“We don’t clearly understand the complex processes of what cells are doing. I am aiming to understand the cellular contributors to bone repair and use that knowledge to improve outcomes,” he says.

Dr Schindeler and his colleagues were the first in the world to show that muscle cells are able to contribute to the healing of traumatic open fractures. The ORBU is continuing to investigate the role of muscle cells in healing other orthopaedic conditions, as well as finding new ways to mobilise these cells to improve repair. It is hoped that the research will ultimately be translated into new therapies.

Another area of interest is neurofibromatosis type 1 (NF1), a genetic disorder resulting in tumours as well as a variety of orthopaedic problems. Children with NF1 can develop a debilitating condition, called congenital pseudarthrosis, where a leg fracture fails to heal, and amputation is not uncommon.

With funding from the NHMRC and the Children’s Tumor Foundation in the United States, Dr Schindeler is studying the mechanism of bone defects in children with NF1, and has demonstrated that there are problems both in bone formation and bone resorption.

The ORBU is now planning a multi-centre trial to use a combination of bone morphogenetic proteins and bisphosphonate medication to try to achieve better outcomes for these children.
The Children’s Hospital at Westmead treats hundreds of children with cancer every year. We see the rarest cases and those that are the hardest to treat. All of our work is underpinned by our research, which aims to translate our understanding of childhood cancer into effective treatments.

In the area of basic research, we look at molecules and cells to work out how we can target cancer effectively. We also investigate the role of gene therapy in treating cancer, and house a large bank of tumour samples which will eventually help us personalise treatment for each individual patient.

In the area of clinical research, we collaborate with research entities throughout Australia and overseas to conduct trials which test the safety and efficacy of new cancer treatments designed specifically for children.

Children’s Cancer Research Unit (CCRU)

Group Leader: Associate Professor Jennifer Byrne (Acting)

Developing the best treatments for childhood cancers

Our 30 research and support staff undertake basic, clinical and translational cancer research. Our aims are to increase understanding of the molecular and cellular basis of childhood and other cancers; to develop new cancer treatments using gene therapy and molecularly targeted approaches, and to facilitate research into childhood cancer by providing high quality clinical specimens, laboratory research platforms and research expertise.

We conduct research into a number of cancer types, focusing on the solid tumours of childhood and adolescence that have a poor patient prognosis like neuroblastoma, brain tumours and childhood sarcomas.

Research
Cancer in children is diagnosed by examining the pathology of tumour tissue and other cells. Often the cancer is not diagnosed until it has reached an advanced stage, while some patients are exposed to highly intensive treatments which do not always work. Tumour Bank research aims to develop “personalised medicine”, where a computational tool will be designed to help clinicians determine the best course of therapy for individual patients. Our aim is to devise genetic profiles for particular tumour samples, enabling clinicians to understand how new patients will respond to different treatments and thus spare high risk treatments for children who don’t need them.

This work relies on samples held by the Tumour Bank. We now have over 25,000 specimens from nearly 3,000 registered patients available, representing over 50 malignancy types and subtypes. Our collection includes solid tumours specimens, whole blood, bone marrow and serial leukaemia specimens, as well as cerebral
spinal fluid and plasma samples. We have recently built tissue microarrays, which will allow for the simultaneous examination of hundreds of tissue ‘spots’ arranged on a microscope slide.

In the area of Cancer Gene Therapy, we have obtained approval to conduct a trial which will address the problem of the toxic side effects of chemotherapy on the bone marrow of children with brain tumours. The project aims to apply a gene therapy strategy, using a DNA repair protein, Methyl-Guanine-Methyl-transferase (MGMT), to provide protection to the bone marrow of these children.

Other important research by our Focal Adhesion Biology team is looking at the mechanisms behind the metastasis of some cancers – how they spread to other parts of the body - while our Molecular Oncology researchers are examining the underlying molecular basis of cancer.

Neuroblastoma Research forms an important part of our work as this common childhood cancer is responsible for 15 per cent of all cancer-related deaths in children. We are currently studying telomeres in neuroblastoma, the special structures that protect the DNA of a cell. This work, a collaborative effort with the Children’s Medical Research Institute’s Cancer Research Unit, aims to help us understand why some, but not all, of these tumours behave so aggressively – and ultimately develop better treatments to improve the cure rate.

Oncology Department

Group Leaders: Dr Luciano Dalla-Pozza, Dr Geoffrey McCowage

Developing the best treatments for childhood cancers

The Hospital’s Oncology Department is a comprehensive paediatric cancer service providing specialised inpatient, outpatient and community-based services to children, adolescents and young adults. All of our clinical activity is underpinned by a clinical trial-centred approach: of the 130-140 new patients presenting every year, over half are enrolled in a clinical trial.

We treat children with complex and often rare cancers who come to us from throughout the state as well as occasionally from interstate and internationally. They receive quality care through an acute program for one to two years, with subsequent follow up for three to five years to monitor progress and assess the effectiveness of their therapy. Sub-specialty programs include leukaemia, bone marrow transplantation and neuro-oncology. A late effects group conducts research on the long-term effects of cancer treatment.

Many childhood cancers are rare and sufficient data to assess new treatments can only be gained through large multi-site international trials. Globally, the dilemma of small numbers for many childhood cancers has been addressed by the formation of international childhood cancer networks. The Oncology Department is a member of several international clinical trials groups, including the USA-based Children’s Oncology Group (COG).

In addition to their cancer research network activities, several members of the Oncology Department are active lobbyists for improving cancer treatments for children in third world countries.

Research

We currently have 60 clinical trials, looking at issues such as leukaemia, quality of life in cancer patients, cancer of the central nervous system, eye cancer, germ cell cancer, sarcomas and Wilm’s tumour of the kidney.
Snapshot: Oncology Department

“Participating in this trial should reduce Logan’s chances of relapse by 30 per cent.”
– Dr Geoffrey McCowage, Senior Staff Specialist in Paediatric Oncology.

Clinical trial offers chance of new treatment for Logan

Logan Britton’s brave battle against cancer has not only restored him to full health – it has potentially helped other children like him to access new and improved treatment which will prevent their cancer from returning.

Quality care provided for children with cancer at The Children’s Hospital at Westmead is underpinned by clinical trials, often run in collaboration with trial groups around the world.

Just over half of the 130-140 new cancer patients who come to the Hospital every year are involved in a clinical trial, and this may be the only way they can access cutting edge treatments for their conditions.

Logan was diagnosed with neuroblastoma, a relatively common and aggressive childhood cancer that forms in the nerve tissue.

After treatment with chemotherapy, surgery and radiation at the hospital, Logan was enrolled in a clinical trial, being run internationally by the US-based Children’s Oncology Group, to study whether a certain antibody could prevent the cancer from reoccurring.

He was given the new treatment for six months and released from hospital last November. Early data from the trial suggests that this will reduce the chance of the cancer coming back by 30 per cent.

“We were happy for Logan to participate – if it didn’t work for him, then maybe they could alter it down the track so it would work for someone else,” says his mother, Merryn.

The Oncology Department is currently participating in 60 clinical trials and is a member of international trials groups including the Children’s Oncology Group, Therapeutic Advances in Childhood Leukaemia, Australian Children’s Cancer Trials, Australian and New Zealand Children’s Haematology-Oncology Group and the International Bone Marrow Transplantation Registry.

“We aim to maintain and promote the clinical trial model of care so we can offer the best available treatment plan to all of our patients through our membership to these trial networks,” says Dr Geoffrey McCowage, Trials Principal Investigator in the Oncology Department.
Dr Loretta Lau trained as a paediatric oncologist but felt limited in her ability to cure children with cancer.

“As a doctor you can only use treatment that’s available for your patients, but that’s as good as it gets. I realised that there were a number of children I knew right from the beginning I couldn’t cure,” she says.

So, like many of the researchers at the Kids Research Institute, she chose to combine both clinical and research work as a way of making a greater contribution to medicine. While she still does some work in the clinic, most of Dr Lau’s time is spent in the laboratory.

“My clinical work informs my research every day,” she says.

“Scientists ask what’s the most interesting thing, but they may not ask questions directly related to patient care. As a practising clinician, you have an insight into how the cancer affects patients and what sort of treatment they need.”

One question that had engaged Dr Lau as a doctor was why some of her young patients with neuroblastoma did extremely well, while in other children the cancer was far more aggressive and the cure rate very low.

In collaboration with the Children’s Medical Research Institute’s Cancer Research Unit, she is looking at telomeres, the structures which protect the DNA of a cell. While in most cells telomeres get progressively shorter to a point when the cell eventually dies, cancer cells are immortal because they somehow maintain the length of their telomeres.

The Children’s Cancer Research Unit is using neuroblastoma cells cultured in the laboratory, as well as tumours collected from neuroblastoma patients, to see how these cells maintain the length of their telomeres, and whether these mechanisms affect the patient’s outcome.

Ultimately, it is hoped that this knowledge will lead to improved treatment for children with neuroblastoma.
The sequencing of the human genome, completed less than 10 years ago, has brought immense opportunity in medicine. By understanding the genetic causes of disease, we are making considerable progress in our ability to diagnose and prevent a large number of conditions.

We aim to understand the biology of genetic disorders, including rare conditions such as Rett Syndrome and Arts Syndrome. All newborns in NSW and the ACT are screened by the NSW Newborn Screening Program for errors of the metabolism. Our work looks at the eye and its development, and aims to develop better ways of conducting genetic testing.

Another important area is gene therapy, which aims to treat genetic conditions in children by replacing faulty genes with healthy ones. Concentrating particularly on the liver and bone marrow, we are on the cusp of translating our knowledge about genetics into targeted therapies for sick children.

Gene Therapy Research Unit (GTRU)

**Group Leader:** Professor Ian Alexander

The answer is in the genes

The Gene Therapy Research Unit, a joint initiative with the Children's Medical Research Institute, is focused on the development of novel gene-based strategies for the treatment of genetic conditions affecting children. To date, four different genetic diseases affecting children have been successfully treated using gene therapy, with many more likely in the near future as research continues in this exciting area.

The liver and bone marrow are two particularly promising targets for gene therapy as many childhood genetic diseases involve these tissues. Our research focuses on the challenge of successfully repairing genetic defects in these tissues using cutting-edge gene delivery technologies (vectors) derived from viruses. We are now at the point where curing genetic diseases in mice is almost routine, and we are on the cusp of applying this progress to humans. Within 12 months, we anticipate involvement in two trials targeting the bone marrow, and within three years a third trial targeting the liver.

**Research**

Our research progress remains strong in all areas, as reflected in continued success in attracting competitive funding from the NHMRC and the publication of our work in the scientific literature.
Over the last year we have made particularly strong progress towards the translation of therapeutic success in mice through to human clinical trials. Having previously reported the successful life-long cure of mice with the urea cycle defect ornithine transcarbamylase (OTC) deficiency, we have now successfully generated mice in which a high proportion of liver cells are of human origin. This has allowed us to begin tailoring our gene transfer technology for the genetic repair of human liver cells and proving that full urea cycle function is recovered.

We have also developed an exciting shRNA-based approach for inducing severe OTC deficiency that has allowed us to produce mice with high ammonia levels in the blood. This in turn has allowed us to better model the therapeutic challenge of treating infants with urea cycle defects, where bringing high ammonia levels down is fundamentally important.

Staff profile:
Dr Robyn Jamieson, Team Leader, Eye and Developmental Genetics Research Group, Western Sydney Genetics Program

Eyes open window on exciting world of genetics research

The sequencing of the human genome nearly a decade ago opened up a new frontier in medicine. Understanding the genetic basis of conditions has led to a raft of new treatment possibilities, including gene and stem cell therapies.

Dr Robyn Jamieson studies the eyes, where these new treatment options may be applied as they are easily accessible and require lower treatment doses compared with other larger organs in the body.

Her work focuses on understanding how eyes develop and how vision is maintained. She and her team are working to find new treatments for blindness, for example in retinal dystrophies, cataracts, glaucoma and developmental eye abnormalities, including very small or absent eyes.

The team runs genetic tests on young children with a range of conditions that affect the eye, with the aim of identifying the underlying genetic cause of their condition – and thus leading to potential treatment.

One of the approaches is to study chromosomes, the structures along which the genes lie. A break or small deletion in a chromosome provides a clue to which genes may be causing the condition.

Recently, Dr Jamieson’s team has discovered three new candidate disease genes for eye conditions by studying chromosomal translocation breakpoints in human patients. The next stage is to identify other human patients with mutations in these genes and to understand how the genes work.

“This work is really exciting,” says Dr Jamieson. “Knowing the full human genome sequence has given us the opportunity to discover new pathways causing disease, which can lead to the development of new and better treatments for diseases. We didn’t really ever realise it would happen this quickly.”
Human Genome Research Program

Group Leader: Professor John Christodoulou

Improving treatment of genetic disorders through research

The Human Genome Research Program, the research arm of the Western Sydney Genetics Program, is devoted to understanding the biology of genetic disorders, with the aim of improving treatment for children.

Our research team consists of a number of research groups, each with its own group leader: the Genetic Metabolic Disorders Research Unit, the Department of Clinical Genetics, the Eye and Developmental Genetics Research Group, the NSW Biochemical Genetics Service, the NSW Newborn Screening Program and the Skeletal and Lysosomal Disorders Research Group.

Researchers from these diverse areas conduct a full range of studies, from basic laboratory research to translational research and clinical studies. Many of our researchers also work directly with patients.

Research

The Genetic Metabolic Disorders Research Unit studies a number of genetic disorders that affect brain development and function. This year we have discovered the genetic basis of MLASA (Myopathy, Lactic Acidosis and Sideroblastic Anaemia) Syndrome. In collaboration with the SIDS and Sleep Apnoea Research Group, we have also identified genes linked to obstructive sleep apnoea in children and further explored the biology of Rett Syndrome.

The Eye and Developmental Genetics Research Group investigates the critical factors in eye development and maintenance of function, and how can these be harnessed to develop better therapies for blinding diseases. This year we have discovered a gene, Twist2, that is critical for normal function of the cornea. Dysfunction of this gene may be a contributing factor to keratoconus, a relatively common condition where there is thinning and distortion of the cornea, making vision very difficult. In collaboration with a group in Boston, we discovered a new gene, TUBB3, required for normal function of the nerves that control the eye muscles. From a family referred with anophthlamia (absent eyes), microphthalmia (small eyes) and coloboma (keyhole abnormality in the iris), we have identified a novel mutation in SOX2.

The NSW Biochemical Genetics Service researches the development of new assay techniques and how to incorporate them into routine use. This work is often carried out in conjunction with the NSW Newborn Screening Department. This year we have developed and validated two new dried blood spot assays for inborn errors of the metabolism. This will allow second tier testing of newborn screening samples without the need to recall the patient for further sampling. In the first half of 2010, we have been able to exclude Maple Syrup Urine Disease in 205 neonates without recall or further sampling, reducing costs and parental anxiety. We have also begun development of a new Tandem Mass Spectrometry technique for urine metabolic testing, which we hope will expand the numbers of conditions covered. As part of our gene therapy research, we have performed biochemical analysis to monitor efficacy of treatment for OTC deficient mice undergoing gene therapy.

The Department of Clinical Genetics at the Hospital conducts predominantly clinically based research. We are currently studying lysosomal storage disorders, Fabry Disease, Pompe Disease and Huntington Disease.
We aim to prevent and treat complications resulting from disorders of the metabolism, such as diabetes.

The Hospital boasts one of the world’s leading clinical paediatric endocrinology research centres, which studies diabetes and osteoporosis. Through basic and epidemiological studies and clinical trials, we are playing an important role in preventing the onset and complications of these conditions.

Other important research involves obesity, Australia’s fastest growing chronic disease in children and adolescents. Our work centres on how to both prevent and treat this condition. We also conduct research looking at the efficacy of exercise in improving metabolism, muscle and bone strength in children with a range of chronic conditions.

Institute of Endocrinology and Diabetes

Group Leader: Clinical Associate Professor Chris Cowell (to March 2010), Associate Professor Kim Donaghue (from April 2010)

Working to prevent diabetes and osteoporosis in children

The Institute of Endocrinology and Diabetes is one of the leading clinical paediatric endocrinology research centres in the world. We conduct basic and epidemiological studies into the causes of childhood diabetes, and conduct clinical trials that aim to prevent or cure diabetes and osteoporosis in children.

The key theme of our research is prevention. Our ultimate objectives are to prevent the onset of type 1 and type 2 diabetes in children; to prevent the development of diabetes complications, and to prevent the morbidity (such as bone pain and fractures) in children with primary and secondary osteopenia.

Research

We are involved in several national and international studies which aim to prevent the complications of type 1 diabetes (the Ad Dit study), to prevent type 1 diabetes in high risk individuals using diet modification (the TRIGR study), and to use intranasal insulin in the national diabetes prevention study (INIT II). Our basic studies investigating the viral causes of type 1 diabetes are demonstrating effects of enteroviruses on beta cells. We are also involved in collaborative studies examining the efficacy and outcomes of new diabetes therapies, including insulin pump therapy and continuous glucose monitoring.

An important area is the study of type 2 diabetes associated with obesity, which now accounts for approximately 11 per cent of all newly diagnosed adolescents with diabetes. We are undertaking two randomised controlled trials to try to reverse the metabolic abnormalities experienced by so
many young people and prevent them from developing into diabetes.

RESIST is comparing the effects of diets that vary in their carbohydrate and protein content on insulin sensitivity in combination with an intense exercise program. VIBRATE is examining the effect of whole body vibration on insulin sensitivity working via stimulation of the lower limb muscles in adolescents with signs of clinical insulin resistance. Recruitment for this study is complete and we are looking forward to analysing the results.

A research highlight has been the development of novel intravenous bisphosphonate treatment protocols for osteopenia and focal bone disorders. Bisphosphonates increase bone mass in children and we currently lead the world in their use. Leading on from our pilot data, we were awarded an NHMRC Project Grant to undertake a multi-centre randomised controlled trial of Zoledronate in children with Perthes Disease of the hip - a five year study that has the potential to alter the treatment of this disorder worldwide. We have also commenced an international randomised controlled trial of Zoledronic Acid in children with glucocorticoid induced osteoporosis. This is the first such study to be undertaken in children and builds on our clinical trial experience.

Whole body vibration training has the potential to revolutionise the prevention and treatment of osteopenia in children. Working through increasing muscle mass and force, vibration training has the potential to both improve mobility and bone mass in children with a variety of disorders. We have commenced trials of vibration training in children with Osteogenesis Imperfecta, Cystic Fibrosis and Mitochondrial Disorders. Protocols are also established for other disorders.

Vitamin D deficiency rickets is a major re-emerging problem in Australia. During an 18 month period, over 400 cases were reported to the Australian Paediatric Surveillance Unit. Rickets was most common amongst recent migrants, children with dark skin colour and girls who were covered for cultural or religious reasons. We have commenced a study to assess the use of high dose (Stoss) vitamin D therapy for rickets that should result in change to routine clinical practice.

Obesity Research Group

Group Leader: Professor Louise Baur

Managing obesity in young people

Our research focuses on the serious public health problem of obesity, which is associated with a range of medical and psycho-social complications. Our researchers and collaborators undertake research that looks at the causes and consequences of child and adolescent obesity, for example how early we see the metabolic complications of obesity in children, and what are the potentially modifiable factors that influence the development of obesity. Other studies look at what types of treatment programs can help children and young people already affected by obesity and how the problem of obesity can be prevented from occurring.

Research

We have undertaken a range of studies looking at options for treating children and adolescents affected by obesity. The Loozit study is a community-based weight management program for obese adolescents. We have recently undertaken qualitative studies of adolescent-parental interactions around weight issues. This suite of studies includes some of the first lower-cost obesity treatment interventions for use in community settings.

This year, we have finalised work on a tool for measuring physical activity in preschool-aged children (Pre-PAQ). Prior to this there were no simple tools available for professionals to use to measure physical activity levels in large groups of three to five year olds.

We have undertaken a range of histological and immunohistochemistry studies looking at fat tissue obtained from healthy children undergoing routine planned surgery. These studies are among the first in the world to look at the developmental changes in fat tissue in children as they grow. They have been undertaken in collaboration with staff at the Garvan Institute in Sydney and at the INSERM in Paris.
Children’s Hospital Institute of Sports Medicine (CHISM)

**Group Leader:** Dr Robert Parker

**Exercise for sick kids**

The Children’s Hospital Institute of Sports Medicine (CHISM) looks at the role of exercise in treating sick kids. Part of our work researchs the role of exercise in children who have musculoskeletal complaints acquired through injury or chronic conditions, while our second focus is improving survival and fitness in children with serious illnesses, such as cystic fibrosis.

The field of exercise medicine is still in its infancy, particularly in terms of treatment of children with chronic disease. However there is good evidence to suggest that exercise interventions can assist in the treatment of children with chronic disease and cardiometabolic disorders. CHISM’s research aims to inform our clinical practice and improve our standard of care for children with these conditions.

**Research**

Our research focuses on the assessment and efficacy of exercise in children with a range of chronic conditions. Our work is conducted collaboratively with other departments at the Hospital as well as at the Royal Children’s Hospital Melbourne, the Royal Children’s Hospital Brisbane and The George Institute for International Health, University of Sydney.

In the area of Juvenile Idiopathic Arthritis, we are examining whether intra-articular steroid injections improve muscle strength in children aged six to 16 years. We are also looking at the fitness, motor skills and quality of life in these patients.

Our research into haemophilia involves examining whether a 12-week exercise intervention improves fitness levels in children with the disease. In addition, we are trying to quantify whether there is an increased risk of bleeding in children with haemophilia when they engage in physical activity.

We are involved in two collaborative studies looking at the role of physical activity in insulin resistance in adolescents. One study is a randomised controlled trial designed to examine the effect of two different dietary interventions and exercise on insulin resistance. The second study is designed to examine the effect of whole body vibration training on insulin sensitivity in overweight adolescents.

“There is good evidence to suggest that exercise interventions can assist in the treatment of children with chronic disease.”
Prevention is as important as curing disease in medical research. Associate Professor Kim Donaghue and her colleagues at the Institute of Endocrinology and Diabetes are working not only to prevent the complications of diabetes, but to stop children from developing the disease in the first place.

Associate Professor Donaghue is co-investigator in a national diabetes prevention study that is investigating whether giving intranasal insulin to at-risk children will turn off the immune process in their pancreas which causes them to develop type 1 diabetes.

Children are recruited because they have a family member with type 1 diabetes and test positive to antibodies to the pancreas, but have not yet developed diabetes themselves. The hope is that a small dose of insulin (inhaled through the nose) every week for a year will act as a vaccine to induce tolerance to the disease.

Another important study being undertaken by the Institute, the TRIGR Study, is trying to reduce the chance of children developing type 1 diabetes by removing cows’ milk from their diet once they are weaned.

“We have much better methods of controlling diabetes and managing blood sugars, but it’s still a very demanding condition to manage,” says Associate Professor Donaghue.

“Not only are we trying to prevent children from developing diabetes, but we are also understanding more about why children get diabetes complications, which will result in better methods of controlling the disease.”

There are some novel ways of doing this. One study aims to prevent diabetes complications by examining the geometry of the blood vessels at the back of the eye to pick up children who are at risk. Another uses ultrasound to measure the thickness of the plantar fascia, the tissue at the base of the foot, as a measure of long-term effects of glucose and lipids on tissue.

Associate Professor Donaghue is also involved in a large international multi-centre study, the AdDit study, which is looking at whether giving statins and ACE inhibitors to adolescents with diabetes will prevent them from developing kidney and heart problems as they age.
**Good vibrations stave off the complications of obesity**

Whole body vibration training – where patients stand on a rapidly vibrating platform – has been used for some time in adults to boost muscle strength and bone mineral density. But in a world first, the Kids Research Institute is trialling its use in improving insulin sensitivity in overweight adolescents at risk of developing type 2 diabetes.

It is believed vibration training works by causing multiple contractions of the muscles, similar to resistance training. It is the pull of the muscles on the bone that is thought to increase bone mineral density.

Muscle tissue takes up glucose and thus reduces the burden on the pancreas to produce insulin. The VIBRATE study, run by the Institute of Endocrinology and Diabetes, is testing whether toning the large muscles of the calf, thigh and buttocks with whole body vibration will therefore improve insulin sensitivity.

"Obese adolescents are at particular risk of developing type 2 diabetes. We are targeting them at an early stage where we can actually intervene and prevent them from developing the disease," says Endocrine Research Fellow Kim Ramjan, who is conducting the study as part of her PhD.

Overweight children aged 10 to 18 years with evidence of insulin resistance were randomised into two groups. Both were given lifestyle intervention involving nutritional advice from weight management dietitians, exercise prescription from a sports medicine physician and fitness testing.

One group of children was also given a Galileo™ vibration platform to take home and use for nine minutes a day over a period of three months.

The trial was recently completed and the results are being analysed to see if lifestyle intervention and additional vibration training has more of an impact on insulin sensitivity than lifestyle intervention alone.

Anecdotally, Dr Ramjan has noticed that many of the children who took part in the vibration training decreased their waist circumference, a result which has also been seen in small animal studies.

Eleven year old Sidhant Vashisht joined the VIBRATE study weighing 80 kg. After three months he lost 3 kg and 3 cm around his waist. He enjoyed using the vibration platform every day. "It was a fun thing to do and by fixing his metabolism it kept on helping him the whole day," says his father, Vikas.
Stream 6
Renal Medicine and Transplantation

Research is undertaken into new treatments for kidney disease, new methods of diagnosis, and improving the quality of life for children with kidney disease. Since 2000, the Cochrane Renal Group has been housed here, assessing all trials globally concerning kidney diseases and analysing and publishing their data.

The Centre for Kidney Research conducts laboratory work to help understand the genetic basis of kidney disease and the immune response to transplantation. The renal laboratory has also expanded its work to investigate issues concerning tolerance in kidney transplantation and islet transplantation to treat type 1 diabetes.

Centre for Kidney Research

Group Leaders: Professor Jonathan Craig, Associate Professor Stephen Alexander

Curing kidney disease

Our research focuses on the better treatment of kidney disease and on improving diagnosis and screening of paediatric illnesses and adult onset disease. Many of our studies have lead to changes in clinical practice.

Research

In 2009, the results of the PRIVENT Trial were published giving general practitioners and paediatricians good quality evidence to help them decide how best to treat children who are at risk of repeat urinary tract infections. The trial demonstrated the utility of antibiotics in protecting against further urinary tract infections.

This year, we started to analyse the enormous quantity of data collected in the FEVER Study, which aimed to find new diagnostic methods for children with serious bacterial illness. In April 2010, the results of the first two years of the study were published and received considerable media attention. We showed that using modelling of symptoms with which young children present when febrile and unwell to the Emergency Department results in improved detection of children with serious bacterial infection and could lead to better treatment, compared with how children are currently managed.

The Detecting Bowel Cancer through Screening in Chronic Kidney Disease (DETECT) Study is a new research study involving screening and early detection of bowel cancer in people with kidney disease – who have a much greater risk of colorectal cancer. Findings from this study will inform clinicians and policy-makers about the optimal methods of early cancer detection in this high risk population. People with chronic kidney disease have reduced life expectancy secondary to a diverse range of comorbidities such as cardiovascular disease. Little however is known about the quality of life of people with reduced kidney function and co-
existing chronic illnesses such as cancer. The Quality of life of people with Kidney disease (QuICK) Study aims to assess the utility-based quality of life of people with kidney disease and kidney disease and cancer. Findings from this study will be used in future economic analyses of intervention about the best use of limited resources in the context of chronic kidney disease. We conducted a study that explored experiences and perspectives of adolescent kidney transplant recipients and to elicit strategies from them on ways to improve service delivery and support following kidney transplantation.

The renal laboratory has been working on the issues of tolerance in glomerulonephritis in particular the use of Tregs (a special kind of white blood cell) as a treatment for kidney disease. It has also expanded its work in transplantation to issues related to tolerance in islet and kidney transplantation. We continue to collect DNA from families for the Kidney Gene Bank and are investigating a number of kidney-related genes.

Staff profile:
Dr Min Hu, Research Scientist, Centre for Kidney Research

Dual immune systems can prevent rejection in organ donation

The main problem with transplantation is that recipients have to take immune-suppressant drugs for the rest of their lives to prevent their bodies rejecting the new organ.

But new results from the Kids Research Institute may prevent that happening.

The aim is to give bone marrow from the donor to the recipient as well as the donated organ. The donor’s bone marrow cells grow and multiply in the recipient, allowing the two immune systems to provide tolerance to the new organ.

The chemotherapy drug, BCNU, is used to suppress the host immune system, but the problem is that this damages DNA. Dr Min Hu, a Research Scientist at the Centre for Kidney Research, has shown that by using a protective protein, MGMT, to limit BCNU’s effect on donor bone marrow, she can increase the amount of donor immune cells allowing tolerance.

She has shown that, in mice, long-term dual immune systems can be achieved by using donor bone marrow containing MGMT following BCNU drug treatment.

“Specific transplantation tolerance has been achieved so the recipient can still fight other diseases,” Dr Hu says.

“This has been achieved in the animal model, so the next step would be to apply this research clinically.”

As a result of her work, Dr Hu was awarded the International Basic Science Mentee/Mentor Travel Award by The Transplantation Society to attend The International Congress of The Transplantation Society in Vancouver.

She has been working at the Kids Research Institute for 10 years, having arrived in Australia from Shanghai in 1999. She completed her PhD in 2008 and has developed this study with help from Professor Ian Alexander, Professor Peter Gunning, Dr Geoff McCowage and Belinda Kramer and is now working on islet transplant tolerance for treating diabetes.
Long-term antibiotics proven to prevent recurrent urinary tract infections in children

As a baby, Jamie Bertumen was forever suffering from high temperatures and vomiting. He was treated in hospital several times and at six months old he was diagnosed with bladder reflux.

The cause of his illnesses had been recurrent urinary tract infections (UTIs), which had compromised his kidneys. He was circumcised and placed on antibiotics for two years to prevent another infection.

Since the 1970s, doctors have been using low dose antibiotics long term, sometimes for as long as 10 years, to prevent infections in children with recurrent UTIs. But until recently, there was no evidence that this strategy worked.

The Centre for Kidney Research has completed the world's largest study to see whether long-term antibiotics prevent UTIs in children. The PRIVENT trial was an NHMRC funded, multi-centre double blind randomised controlled trial in which antibiotics were given daily to one group of children for one year, while a second group received a placebo.

The trial discovered that antibiotics did significantly reduce infections, but only by a small percentage. The children who took antibiotics had a 13 per cent chance of a repeat infection, while children who took the placebo had a 19 per cent chance.

“These findings have changed the way children with predisposed infection are treated in two ways,” says Professor Jonathan Craig, Head of Clinical Research at the Centre for Kidney Research.

“Those families and doctors who, when faced with the information that we didn’t know whether it worked or not, have now decided to go on it. Others say ‘Yes it works, but the benefit is really quite small so I’d rather wait’.”

The study found there were few side effects associated with long-term antibiotic use – in fact, adverse events such as stomach upsets were more common in the placebo group.

For Jamie, antibiotics have changed his life. At nearly five, he is now infection free and looking forward to starting school.
Stream 7
Infectious Disease and Immunology

Our research is helping understand the immune system and finding ways of preventing infectious diseases.

An important area of research involves immunisation and vaccine preventable diseases. As well as conducting vaccine trials to produce safe and effective vaccines, we play an important public health role, with our work informing policy regarding the spread of disease and epidemics.

Other research looks at the transmission of perinatal infections from mother to unborn child, allergic disorders, which are increasing among Australian children, and the role of viruses in infectious disease.

National Centre for Immunisation Research and Surveillance of Vaccine Preventable Diseases (NCIRS)

Group Leaders: Professor Peter McIntyre, Professor Robert Booy

Preventing disease through vaccination

Our research informs policy and practice in immunisation through a wide range of research at the population and clinical levels. We produce national reports on vaccine preventable diseases, immunisation rates and adverse events following immunisation and conduct national serosurveys. The Clinical Research group conducts vaccine trials.

Research
In 2009, NCIRS, in coordination with Australian Paediatric Surveillance Unit (APSU), continued the Paediatric Active Enhanced Disease Surveillance (PAEDS) demonstration project for active, hospital-based surveillance. Its aim is to capture detailed clinical data on severe potential adverse events following immunisation and severe vaccine-preventable diseases. Four tertiary paediatric hospitals are involved in the pilot – The Children’s Hospital at Westmead, the Royal Children’s Hospital in Melbourne, the Women’s and Children’s Hospital in Adelaide, and Princess Margaret Hospital in Perth.

We conducted several important studies on influenza. These included studies related to influenza and influenza vaccine among children in daycare centres, funded by the Australian Research Council, which will look at the economic and social impact of influenza vaccination. We have also run a trial of swine flu H1N1 influenza vaccine and two treatment trials of antivirals, one funded by NHMRC. NCIRS was instrumental in performing rapid surveillance follow-up required to
The Centre for Perinatal Infection Research (CPIR) has made significant contributions to the understanding and management of perinatal infections.

**Group Leader:** Associate Professor Cheryl Jones

**Protecting newborns from infection**

Perinatal infections contribute to a large burden of childhood disease and disability and a large but unmeasured burden of miscarriages, stillbirths and premature births. However, these infections go virtually unrecognised in Australia.

Our research has highlighted the extent of medically important congenital and perinatal infections that are not recorded by Federal reporting systems. We have also conducted research examining attitudes to and knowledge about immunisation against influenza among parents and against Human Papilloma Virus among health care providers.

We are currently trialling a new vaccine against Dengue virus in adults, which is the second most common cause of hospitalisation after returning from holiday in the tropics. Dengue fever causes 25,000 to 50,000 deaths annually, the majority in children. The vaccine is expected to be available within two to three years and will benefit children worldwide.

We are also leading research into HIV positive children in Tanzania, who show extremely high rates of coverage of the pneumococcus bacteria in their throats. HIV positive children are at risk of dying from pneumonia as a cause of this bacterium throughout their lives, rather than just in infancy. Our work demonstrates for the first time the importance of vaccination of older children with HIV against pneumococcus.

We have demonstrated two important genetic factors which explain infection with Haemophilus influenzae type b (Hib), another common cause of pneumonia in children. While Hib is under control in Australia, this understanding of the genetics of infection helps us to understand children’s predisposition to other viruses.

**Research**

Our overall research objective is to improve diagnosis and treatment of perinatal infections and to develop novel therapies to prevent or treat them.

One aspect of our research focus is to determine the reasons why the immune system of a newborn infant does not protect it against certain viral infections like herpes simplex virus (HSV) or cytomegalovirus (CMV).

This year, we have made a major breakthrough in identifying how skin cells are infected with HSV. This discovery - the result of a joint collaboration between the Kids Research Institute, Sydney Medical School at Westmead, the Centenary Institute and the Westmead Millennium Institute - may have significant implications for a vaccine being available for the virus.

We are also investigating the role of cells in the skin early in the immune response against HSV. This work will allow us to develop ways to protect against viruses that enter through the skin or mucosa from the first weeks of life.

The Sydney Emerging Infectious Diseases and Biosecurity Institute (SEIB) was established late in 2009. We are instituting two multidisciplinary studies to define effects of important emerging infections, such as swine flu H1N1 and viral encephalitis in children.

Our overall research objective is to improve diagnosis and treatment of perinatal infections and to develop novel therapies to prevent or treat them.
Department of Infectious Diseases and Microbiology

**Group Leader:** Associate Professor Alison Kesson

**Understanding viral infections**

Our aim is to understand the basic biology of viral infections in children. We study how viruses interact with cells and how they evade the body’s immune response.

We also investigate laboratory diagnostic methods and the epidemiology of childhood viral infections in our population.

**Research**

This year we have been looking at the epidemiology of [norovirus](https://www.flaviviruses.org) and [astrovirus](https://www.flaviviruses.org), both of which cause diarrhoea in children. Our primary aim is to study the relative contribution to disease of these two viruses in Australia since the recent introduction of universal vaccination against rotavirus. We are developing a new molecular diagnostic test, the ELISA diagnostic test, with the aim of improving diagnosis. We are also helping to conduct genetic studies to determine relationships within the virus groups and establish whether there are similar or multiple strains of these viruses in society.

Basic research involves studying the immune response to viral infections and how [flaviviruses](https://www.flaviviruses.org) have evolved mechanisms to avoid recognition by the body’s immune system. Recent work has shed light on the mechanism of immunopathology associated with flavivirus infections and the possible mechanisms of virus-induced auto-immune disease.

More recent work is looking at the role of genes in the cellular processes that occur when cells are infected with flaviviruses.

Department of Allergy and Immunology

**Group Leaders:** Associate Professor Alyson Kakakios, Dr Melanie Wong

**Beating allergies**

Research, along with teaching and clinical activities, comprises an integral part of our work. Our research focuses on two major areas: food allergy and eczema, and primary and secondary immunodeficiency.

**Research**

The **BEAT: Beating Egg Allergy Trial** aims to determine whether the introduction of egg into the diets of infants at high risk of atopic disease at four months of age is associated with a decrease in egg sensitisation and clinical egg allergy. We are also investigating baked egg challenges and are in the process of coordinating a number of studies looking at the prevention and treatment of severe eczema.

We have continued collaborative research looking at the mechanism of B cell maturation and antibody formation in the context of [primary immunodeficiencies](https://www.flaviviruses.org). Together with the Bone Marrow Transplant Service, we are investigating early serologic markers of graft versus host disease as well as immune reconstitution post transplant. We are continuing to expand the range of specialised tests available locally for the diagnosis for rare primary immunodeficiencies.
Staff profile:
Professor Peter McIntyre, Director, National Centre for Immunisation Research and Surveillance of Vaccine Preventable Diseases (NCIRS)

Whooping cough vaccine trial aims to protect babies from birth

The pertussis (whooping cough) epidemic that has swept Australia since 2008 has now claimed the lives of four babies, all of whom were too young to receive pertussis vaccine. Those most at risk from severe pertussis are small babies. Currently the first vaccine dose is not given until two months of age, with stronger protection not achieved until a second shot at four months.

Professor Peter McIntyre is Director of the National Centre for Immunisation Research and Surveillance of Vaccine Preventable Diseases (NCIRS), which is working hard to close that window of vulnerability.

A randomised controlled trial is testing whether a vaccine with just pertussis given at birth, followed by the usual six-in-one combination vaccine, containing diphtheria, tetanus, Hepatitis B, Haemophilus influenzae type b, polio and pertussis, given at six weeks rather than eight weeks, will provide full protection to babies by two months.

“Our central aim is to protect newborn babies as early as possible against whooping cough. There is some encouraging evidence that just one dose may be enough to protect against dying from pertussis, so seeing whether a dose at birth can hasten immune responses is a really important area and this is the only study of its kind in the world,” says Professor McIntyre.

NCIRS, in its national role, has a strong track record of facilitating and collaborating with the work of other Australian research groups in the area of vaccine-preventable diseases. Two examples of this are pertussis and ear disease in Aboriginal children.

NCIRS is collaborating with researchers from the University of NSW and Westmead Hospital to obtain pertussis organisms from infected infants and their family members to see whether there has been a change in the nature of the bacterium that may have contributed to its spread. Along with researchers from the University of Melbourne, it is investigating the spread of pertussis within families.

Professor McIntyre is leading the ear disease component of the SEARCH study, being conducted by the Sax Institute and the Aboriginal Health and Medical Research Council among Aboriginal children attending community-controlled health services in New South Wales. He is also one of the chief investigators in the team, led by Menzies School of Health Research in Darwin, which is studying whether using two conjugate pneumococcal vaccines together is better than either alone in preventing severe ear disease in Aboriginal children in the Northern Territory.
Clinical sciences research aims to improve the evidence base and treatment options in a wide range of specialities offered at our Hospital. We look at rare diseases and provide surveillance of the rare complications of more common disorders. We are active in the areas of respiratory medicine, sleeping disorders and SIDS. We research optimal care for sick newborn babies, and we study rehabilitation for children with brain injuries and cerebral palsy. We are also boosting research into adolescent medicine, which has long been a specialty of the Hospital.

Research into the delivery of health services aims to provide an evidence-based approach to the way we treat sick children. For example, we conduct research into trauma care with the aim of preventing child injury and offering the best services possible to the children who come to our Hospital. We also study how to improve nursing services, and work to translate research findings into medical practice through publications and publicity.

Australian Paediatric Surveillance Unit (APSU)

Group Leaders: Professor Elizabeth Elliott, Dr Yvonne Zurynski

Understanding rare childhood conditions

We conduct research into rare childhood conditions, an area where there are often significant gaps in knowledge. We provide vital information on a range of rare conditions or rare complications of more common conditions, including infectious, vaccine-preventable, mental health, congenital and genetic conditions and rare injuries for which detailed national data are not available from other sources. Our research outcomes contribute to the development of public health policy and inform clinical practice.

Over 1,300, or about 92 per cent, of all paediatricians and other child health clinicians in Australia participate in monthly APSU surveillance by providing de-identified data.

Research

Our excellent track record in influenza surveillance and the establishment of the Paediatric Active Enhanced Surveillance (PAEDS) system enabled a rapid response to the 2009 swine flu H1N1 pandemic. With an H1N1 Emergency Grant from the NHMRC, our quick and timely collection of data showed that 30 per cent of children admitted to hospital with H1N1 developed serious complications, including neurological and respiratory problems. About half of these children did not have any chronic medical problems, supporting the need for vaccination of all children, not just those with underlying chronic disease.
We established new national studies into serious childhood conditions, such as Systemic Lupus Erythematosus and Neonatal Hyperbilirubinaemia, or severe jaundice. The information collected will enable paediatricians to improve treatment for children with these conditions.

We began national data collection on subdural haematoma (SDH) in children aged less than two, which is a rare but significant cause of morbidity and mortality in infancy. The condition can occur due to traumatic delivery, trauma in utero, accidents or non-accidental trauma. Sadly, the most common cause of SDH in children aged less than two years is inflicted, non-accidental injuries which are preventable. Despite the seriousness of SDH, there is no national data to describe the size and scope of this problem. Our work will enable international comparisons with New Zealand and Britain, which have already established national data sets.

On behalf of the National Rare Diseases Working Group, we drafted a National Plan for Rare Diseases and are currently consulting with key national organisations to seek comment and input. We have also made important strategic links with organisations that support families affected by rare diseases such as the Steve Waugh Foundation, SMILE Foundation and Association for Genetic Support Australasia (AGSA). With their support we started a program of research into the impacts of rare diseases on families, clinicians and health services to provide information that will support the development of new health and support services and to underpin advocacy.

Grace Centre for Newborn Care Research Group

**Group Leaders:** Professor Nadia Badawi, Associate Professor Kaye Spence

**Improving care for newborn babies and their families**

The Grace Centre for Newborn Care is a neonatal intensive care unit (NICU) which looks after approximately 600 infants each year from NSW, the ACT and islands surrounding Australia. The unit specifically cares for babies with surgical problems, cardiac or complex medical conditions.

The focus of our research is on improving the quality of care and long-term outcomes for newborn babies undergoing surgery and family support within the NICU and following discharge of their infant. Much of our research has resulted in the development of policies and guidelines, for example in the area of newborn pain management. We expect that our study into long-term outcomes for infants undergoing major surgery will change the recommendations for systematic multidisciplinary follow-up in Australia.

**Research**

**The Daisy Study** is looking at the long-term quality of life of babies who are subjected to complex surgery at earlier ages and smaller birth weights. Recruitment to the study and the first year follow-up are now complete. Major surgery in infants was found to be significantly associated with lower neurodevelopmental scores at one year of age. This data has important implications for interventions and clinical review in the first year of life.

Another study is examining the **social and emotional burden** on families of having an infant who requires neonatal surgery. This study is being undertaken in collaboration with the University of Melbourne and the Royal Children’s Hospital. Our goal of supporting families has led to a study of post traumatic stress in parents who have a baby in intensive care and following discharge. Current research focus is on dyadic analysis of couples experiencing grief or traumatic stress.

Nurses provide expert clinical care and, as part of our research philosophy, we support the integration of research into practice. A study examining **nursing knowledge on patient outcomes and decision making** is a collaborative project with all the NICUs in NSW. The Clinical Neonatal Nursing Research Fellowship was established six years ago and continues to provide opportunities for a clinical nurse to undertake a small study and gain an understanding of the research process. The current incumbent is undertaking a randomised controlled trial of a new device for securing endotracheal tubes in ventilated infants.

Although the survival rate of preterm infants has increased, many of them still suffer from long-term respiratory problems, such as the development of Chronic Lung Disease (CLD). We are studying the role of Clara Cell Secretory Protein (CCSP) in CLD with the aim of preventing the condition.

We are assessing the role of diagnostic ultrasound prior to transporting infants from peripheral hospitals; we are carrying out population-based research in the area of newborn encephalopathy and cerebral palsy in collaboration with the Cerebral Palsy Institute, and we are re-developing ways of measuring and reporting key clinical outcomes to clinical cooperation between the NICUs within NSW and the ACT.
Respiratory Medicine Research Group

Group Leaders: Professor Peter van Asperen, Dr Karen McKay, Dr Hiran Selvadurai

Helping kids breathe easy

Our research focuses on the causes, diagnosis, investigation and treatment of respiratory illness in children, in particular cystic fibrosis, asthma and the respiratory consequences of extremely pre-term birth. We have established collaborative research projects with our departmental colleagues specialising in sleep medicine, as well as a number of other departments of the Hospital, including Gastroenterology, Endocrinology, Cardiology, Anaesthesia, Oncology, CHISM and The Western Sydney Genetics Program (WSGP).

We also work in partnership with many of the children’s hospitals in Australia and New Zealand, as well as research institutions internationally and the pharmaceutical industry.

Research

One of this year’s highlights was the foundation of the Exercise Testing Laboratory, located within the Department of Respiratory Medicine. In collaboration with the CHISM Exercise Testing Service, this enables us to assess children with chronic lung diseases and other chronic diseases which may impact on cardiopulmonary functioning. It can also be used as a means of assessing the benefits of new treatments. At present, we are using the laboratory in a collaborative study with the Department of Endocrinology and WSGP to evaluate the effectiveness of vibration plate training in children with chronic diseases.

We have recently completed a study in conjunction with the Department of Respiratory Medicine at Sydney Children’s Hospital looking at the incidence of pneumococcal (a certain type of bacteria) infections in children with empyema (‘fluid’ in the chest around the lungs). This study used a simple ‘dipstick’ method of detecting this bacterium, in the hope that in future this method could be used at local hospitals, obviating the need to transfer at least some children with this condition to children’s hospitals.

We conducted a review of complementary therapy used by Australian children with asthma, as well as a survey of parental expectations of physician knowledge and attitude toward these therapies. We have continued our investigations into the utility of a new non-invasive method of measuring lung function in children with asthma. This method does not require the cooperation of the child, a perennial problem in measuring lung function in childhood.

We have completed assessments of children taking part in an NHMRC-funded study of the utility of bronchoalveolar lavage as a means of directing antibiotic therapy in infants and very young children with cystic fibrosis. We are also investigating the short-term effect of anaesthetics on the respiratory and general health of children with cystic fibrosis, and we have recently completed a study of the effectiveness of the inhaled dry powder mannitol in assisting clearance of secretions during cystic fibrosis exacerbations.

In partnership with the pharmaceutical industry, we have begun studies of both ion channel modifiers and genotype-specific therapies in cystic fibrosis. These are the first large scale multinational studies of therapies designed to correct the basic defect in cystic fibrosis rather than just control symptoms and improve lung health, and may prove to be the first in a line of new therapies available for this life-limiting condition.

SIDS and Sleep Apnoea Research Group

Group Leader: Associate Professor Karen Waters

Towards a good night’s sleep

Our research focuses on the causes, complications, investigation and treatment of sleep apnoea and sleep disorders in children. We are associated with the Sleep Disorders Unit at the Hospital – established as a research facility with the assistance of the (then) National SIDS Council of Australia – and the David Read Laboratory at the University of Sydney.

The two main themes of our research at the University of Sydney are physiological studies of exposure to intermittent hypoxia and nicotine during early development, and the neuropathological consequences of these exposures, as well as comparative studies to evaluate their potential involvement in SIDS.

At the Hospital, our research covers many aspects of the diagnosis and treatment, including treatment outcomes of infants and children with obstructive sleep apnoea. We use sleep studies to document the presence and severity of the condition as well as
the effectiveness of treatment interventions such as medication, surgery or nasal mask Continue Positive Airway Pressure (CPAP) machine.

Research
The SIDS and Sleep Apnoea Group is the coordinating centre for a multicentre Paediatric Research Group in Australia. This is a major advance in commencing proper evaluation through randomised trials to evaluate treatment outcomes in paediatric sleep apnoea. We have completed recruitment for a randomised controlled trial study of the effectiveness of

Staff profile:
Dr Yvonne Zurynski, Deputy Director, Australian Paediatric Surveillance Unit (APSU)

Research into children’s car seats leads to new laws

Dr Yvonne Zurynski spends her time studying childhood injury – and how to prevent it. This year, she and her colleagues at the Australian Paediatric Surveillance Unit (APSU) scored a major victory when the Federal Government used the Unit’s research findings to draft important new laws on car safety restraints for young children.

Previously, car restraints were mandatory only for babies up to 12 months of age. But a national APSU study of very severe injuries in children who were involved in car accidents while restrained revealed that most of them were either not in the correct car seats or were using the seats inappropriately.

The study found about 90 per cent of injured children aged between four and seven were using adult seatbelts and often tucking the shoulder strap behind their back or under their arm. In a car crash, they not only received serious head and spinal injuries from being thrown forward, but they also suffered severe abdominal injuries from the pressure of the seatbelt across their tummy.

“Two children ended up with paraplegia. Some of the abdominal injuries resulted in kids needing surgery and sometimes repeat surgery to repair intestinal tears, and injuries to their liver and spleen,” says Dr Zurynski. “Using the correct child restraint is such a simple thing to do. We all get complacent because these accidents are rare occurrences, but if you do have that accident and your child isn’t restrained properly, the consequences can be devastating.”

Based on the report filed by the APSU and data from other sources, the National Transport Commission has introduced new laws stating that children aged one to four must travel in an approved child restraint with a five-point harness, and children aged four to seven must sit in an approved booster seat.

“This will prevent serious injuries. Now we need to get the message across to parents and carers,” Dr Zurynski says.

Deputy Director of the APSU for the last five years, Dr Zurynski is now studying the extent of subdural haematoma in children under two – severe brain injury most commonly caused by abuse. She hopes that a clearer picture of the demographics of the problem will enable her and a team of experts in child protection and neurosurgery to target specific groups for intervention so that these injuries, too, can be prevented.
“For the first time, we now have drugs that treat the basic problem of cystic fibrosis.”
– Professor Peter van Asperen, Head of the Department of Respiratory Medicine

Jack jumps towards a bright future

At just 10, Jack Christie’s commitment to his Olympic snowboarding dream is rivalled only by his commitment to staying healthy.

Jack was diagnosed with cystic fibrosis at six weeks old following a routine heel prick test. Australia was the first country to introduce comprehensive screening of newborns for the disease, a lifelong and life-threatening condition which results in the lungs becoming repeatedly infected and clogged with mucus.

Jack follows strict medication and physiotherapy programs every day. His entire family concentrates on staying fit and healthy and maintains rigorous hygiene to avoid infection. Over the years, Jack has been hospitalised several times with chest infections, but in general his health remains good.

He was one of the first children to participate in a 10-year NHRMC-funded study by the Respiratory Medicine Research Group into ways of diagnosing and treating lung infections from birth to five years. He has also been enrolled in a new study into ways of clearing mucus from the lungs.

When he’s not working on his disease, Jack is either at the snow fields – which he visits every weekend - or practising his snowboarding manoeuvres for an hour every morning on the trampoline at home.

He has won three snowboarding titles this year and hopes to compete at the 2018 Winter Olympics.

“Cystic fibrosis doesn’t affect his ability. If we keep him nice and healthy, the better he does and the better his lungs do,” says his mother, Kate.

Thirty years since newborn screening for cystic fibrosis was introduced in Australia, management of the disease is still confined to clearing the lungs of mucus and treating infection. However researchers internationally have, for the first time, identified a treatment for the basic problem in cystic fibrosis.

A trial of the treatment in older children is underway internationally, including at the Kids Research Institute. If these children do well, then it is anticipated the treatment will be introduced for younger children in order to prevent the destruction of their lungs.

“They will still have cystic fibrosis but they will have an effective treatment,” says Professor Peter van Asperen, Head of the Department of Respiratory Medicine.

“It means we could really exploit that benefit of picking up babies early on and prevent lung damage by using treatments which overcome the underlying defect rather than treating the consequences of that defect, as we currently do. It’s an exciting prospect.”
Department of Adolescent Medicine

**Group Leaders:** Clinical Associate Professor Susan Towns, Professor Kate Steinbeck (from April 2010)

**Putting adolescents first**

The Department of Adolescent Medicine has a strong clinical research program which focuses on informing and evaluating our clinical practice in treating issues specific to adolescents. The newly established Academic Department of Adolescent Medicine, led by Professor Kate Steinbeck, the inaugural Medical Foundation Chair of Adolescent Medicine, aims to integrate current research and add to evidence-based research required to inform clinical practice.

**Research**

The **Academic Department of Adolescent Medicine** is studying how puberty hormones are related to adolescent health and wellbeing; transition in chronic illness from paediatric to adult care; obesity and insulin resistance; the long-term effects of cancer therapy in childhood cancer survivors, and the hospitalised adolescent.

The **Centre for Research into Adolescent's Health (CRASH - Eating Disorders and Neuroscience)** conducts an extensive range of research projects in eating disorders.

In collaboration with the Brain Dynamic Centre, a series of projects examine the neuropsychological and neurobiological aspects of ADHD and the impact of stimulant and other medications. Other research is looking at drug treatments for autism, in collaboration with the Royal Children's Hospital in Melbourne.

The **Complex Adolescent Clinic** is close to completing a large scale project on the treatment of complex medico-psycho-social conditions such as pain disorder and post-viral fatigue. We have also conducted several multidisciplinary research projects in the areas of chronic illness and transition. For example, we are participating in an examination of how cancer influences the transition from adolescence to adulthood, and we have recently conducted an evaluation of the Hospital’s services supporting transition to adult care.

Adolescent risk-taking behaviours such as **drug, alcohol and tobacco** use is another area of interest. Teen-Link (a collaborative service with Sydney West Area Health Service for teenagers of parents who are on drug treatment) has recently undertaken research on awareness of child protection issues in adult drug and alcohol workers. The Service of Addiction Medicine for Youth (SAMY) has studied Emergency Department management of young people at risk of drug and alcohol problems. An audit of this new service is planned for next year.

We are involved with several multi-disciplinary projects that seek to find new, cost-effective solutions for **weight loss** in adolescents.

The newly established Academic Department of Adolescent Medicine aims to integrate current research and add to evidence-based research required to inform clinical practice.

**Kids Rehab (formerly the Department of Rehabilitation Medicine)**

**Group Leaders:** Dr Stephen O’Flaherty, Dr Angie Morrow

**A better quality of life for children with disabilities**

Kids Rehab is a busy clinical unit which currently serves more than 3,000 patients. Over 60 per cent of our staff is actively involved in clinical research, both within our Unit, and in collaboration with the wider community of our Hospital and at a state-wide and international level.

We are currently establishing a new and exciting collaboration with the Developmental Cognitive Neuropsychology (DeCog) Research Unit, an internationally recognised developmental neuropsychology research facility, to establish new projects targeting rehabilitation of cognitive skills in children with brain injuries.

**Research**

We are one of the largest centres providing **botulinum toxins therapy** for children with spasticity in Australia, and our ongoing research in this area has contributed greatly to international knowledge of the outcomes and safety profile of this important treatment modality for children with cerebral palsy.

We have commenced enrolment in a study of deep brain stimulation in children with **cerebral palsy**. This is an exciting opportunity to be at the forefront of work in this new innovation in the management of the challenging problem of dystonia. A national database
to monitor outcomes and adverse events following intrathecal baclofen treatment for spasticity and dystonia was set up in early 2010. Our Department is one of the main centres in Australia providing this intervention.

In other research, we are looking at the pharmacological and cognitive treatment options for children following acquired brain injury. We are trialling a play therapy-based intervention for the management of anxiety in children undergoing botulinum toxin injections, and assessing play skills for children with traumatic brain injury using Child Initiated Pretend Play Assessment (ChIPPA).

We are collaborating with the Royal Children's Hospital in Melbourne on an NHMRC-funded project to examine the acute presentation and resolution of speech and swallowing disorders associated with traumatic brain injury and to develop a clinical tool for assessment of the speech and swallowing disorders in this population.

**Kids Heart Research**

**Group Leader:** Associate Professor David Winlaw

**Beating heart disease in children**

Kids Heart Research is a team of scientists and doctors working together to address clinical problems in the area of cardiac health. Congenital heart diseases affect one in every 100 children, with problems ranging from ‘holes in the heart’ to more complex conditions.

Our research efforts are focused on two main areas: improving our understanding of the genetic basis of congenital heart disease, and finding ways to make heart surgery safer and more effective.

**Research Achievements**

Water accumulation in the body’s tissues, including the heart, was traditionally thought to contribute to poor recovery after surgery. Using a range of experimental models, we have demonstrated that the link between swelling and impaired heart function is not as important as previously thought. The work highlighted the detrimental effect of depriving the heart of its usual blood supply (ischaemia).

It is likely that the way infant cardiac surgery is conducted will be altered as a result of these important findings.

**Kids Critical Care Research Unit (KCCRU)**

**Group Leaders:** Dr Marino Festa, Dr Jonathan Egan

**Improving care for critically ill children**

We conduct research into life-threatening illnesses in babies and children, and investigate the processes used by intensive care clinicians to deliver high-quality care to children and their families in a time-pressured environment. We are located within the Hospital’s Department of Paediatric Intensive Care, the biggest paediatric intensive care unit in Australia, which gives us the ability to contribute to the numbers needed to run adequately powered studies in this field.

Our current work builds on the legacy of past activities and partnerships with local, national and international research groups. Our research is clinically relevant: our multidisciplinary approach to patient care brings together nursing, allied health and medical research priorities and bridges new discoveries in the laboratory to the bedside delivery of quality healthcare for the babies and children in greatest need.
Staff profile:
Dr Paul Robinson, Respiratory Research Fellow,
Respiratory Medicine Research Group

At last – an easy way to measure lung function in children

The smaller airways at the periphery of the lung are involved in important respiratory conditions but are largely ignored by conventional lung function tests, reflecting predominantly larger, more central, airway function. It is also difficult for younger children to perform these conventional lung function tests, as they require cooperation and coordination from the child.

Respiratory Research Fellow Dr Paul Robinson is investigating the utility of two simple, non-invasive lung function tests which measure the function of the peripheral airways and can be performed in a much wider age range. Children perform both tests during normal breathing, usually whilst watching television to distract them from the measurement.

The two tests were developed several decades ago, but were underutilised due to limitations in analysing the data and the impractical size of the equipment. Advances in technology have improved the feasibility and potential utility of these tests in recent years.

“There is good evidence that these tests can be performed in young children but we didn’t know which tests were best suited to which respiratory disease,” Dr Robinson says.

“My research focused on both optimising the way we perform the tests and analyse the data, and on identifying which test is most useful in which disease.”

The first test evaluates the gas mixing efficiency of the lungs, an essential part of subsequent gas exchange. Since most gas mixing occurs in these small peripheral airways, this test indicates how well the lung periphery is working. Dr Robinson’s research has determined that this test is useful for monitoring response to treatment in children with cystic fibrosis.

The second test measures the mechanical response of the lungs to small pressure oscillations. His work has shown that the variable airflow obstruction that is the hallmark of asthma can be detected using this test over several daily measurements and identifies children with poorly controlled asthma.

Dr Robinson’s research is part of an ongoing collaboration with the Woolcock Medical Research Institute in Sydney and the Sahlgrenska Academy in Gothenburg, Sweden. His research has been presented both nationally and internationally. Dr Robinson was recently selected as the 2011 Chair of the European Respiratory Society Infant and Preschool Lung Function Working Group.
**Snapshot: Department of Adolescent Medicine**

“We are focused on developing a biological understanding for conditions which are essentially behavioural, such as ADHD.” – Clinical Associate Professor Michael Kohn, Senior Staff Specialist, Department of Adolescent Medicine

**ADHD: Understanding the cause of behaviour will lead to better treatment**

At 14, Katie is unable to organise her life. She is surrounded by chaos, she cannot concentrate at school, and her family life has suffered as a result. Two years ago, she was diagnosed with Attention Deficit Hyperactivity Disorder (ADHD).

ADHD is increasingly common among adolescents, but its biology is poorly understood.

The standard treatment is stimulant medication to control behaviour, but this approach to treatment does not address the anxiety that occurs in up to a third of patients.

In fact, the medication which is commonly used for ADHD can exacerbate the anxiety.

“People have labelled these kids with just having ADHD and treat it with stimulants, which is oil on the fire for the behaviour,” says Associate Professor Michael Kohn of the Department of Adolescent Medicine.

Associate Professor Kohn is undertaking a number of projects which aim to understand the neuropsychological and neurobiological aspects of ADHD and the effects of medications on them.

One of these, an NHMRC-funded clinical trial, is investigating the link between behaviour and anxiety before and after treatment with medication.

With the use of imaging and physiological measurements, researchers will identify how medications impact both the attention deficit and anxiety, thus tailoring treatment to the individual needs of each patient.

“Our results will almost certainly lead to a personalised treatment approach rather than the standard approach with stimulant medications alone,” says Associate Professor Kohn.

Where conventional treatment seeks to suppress unwanted behaviour in ADHD, the research being conducted by Clinical Associate Professor Kohn and the ADHD Research Team at the Brain Dynamics Centre will identify the brain function underlying the presenting behaviours and permit more specific, and possibly more effective, treatment.

“Getting the medication that would help me concentrate would make all the difference at school – it would mean I could organise myself,” says Katie.
Emergency Department

**Group Leader:** Dr Mary McCaskill

**Acute care for sick children**

Our research focuses on acute paediatric care. In particular, we are looking at trauma and restraints to prevent injury from car crashes; using ultrasound to non-invasively assess shock in children; teaching resuscitation skills; treatment of severe asthma; sports related injuries; febrile children and influenza and the treatment of pain in emergency departments.

We are also part of PREDICT (Paediatric Research in Emergency Department International Collaborative), which includes Australasian paediatric emergency departments.

**Research**

We have been involved in a series of studies on the impact of child restraints on childhood injuries and deaths from car crashes. These studies have resulted in the recent change in NSW legislation mandating the use of car restraints for children.

Department of Anaesthesia

**Group Leaders:** Clinical Associate Professor David Baines, Dr Jonathan de Lima

**Making children comfortable**

Our research aims to improve the safety and comfort of infants and children in the peri-operative period. This work provides an opportunity for clinicians, trainees and students to be involved in evidence-based medicine within the intensive and highly technical operating suite environment.

Our research and audit projects are conducted in close collaboration with the Research Special Interest Group of the Society of Paediatric Anaesthetists of New Zealand and Australia (SPANZA).

**Research**

We have commenced a randomised controlled clinical trial in children who have suffered burn injuries. The trial is looking at whether the drug gabapentin, an NMDA antagonist, can prevent or decrease itch associated with the burn injury.

Malignant hyperthermia is a condition triggered by anaesthetic agents in patients with a genetically-determined muscle disease. We are conducting genetic screening for novel mutations in the RYR1 gene within malignant hyperthermia patients in the Australian population. If the genetic defect can be identified in any given patient, it allows the patient’s family to be screened for the gene and potentially avoid undergoing further more invasive tests.

Other current research interests include the metabolic effects of repeated nitrous oxide exposure in children at risk; peri-operative outcomes in children undergoing multi-level orthopaedic surgery; the effect of anaesthesia on lung function in patients with cystic fibrosis, and pain management in children following intensive care.

We are also running a collaborative pilot project with the Department of Neurology looking at Critical Illness Polyneuropathy in children undergoing cardiac surgery, aiming to see if this occurs in these patients and if it is logistically feasible to study them appropriately.

Department of Nuclear Medicine

**Group Leader:** Clinical Professor Robert Howman-Giles

**Imaging to improve health outcomes**

The Department of Nuclear Medicine is the leading clinical and research paediatric nuclear medicine centre in Australia.

Our research is focused into three areas. We undertake clinical evaluation of nuclear medicine and bone mineral density techniques relating to improvements in patient management. We work on the development of new radiopharmaceuticals and new applications of current radiopharmaceuticals. We also research the development and/or modification of imaging equipment and techniques for new applications or improvements in current uses.
Research
This year we have conducted retrospective reviews of PET/CT studies in patients with paediatric lymphoma and primary bone tumours. This study compared PET/CT with conventional imaging, such as MRI, CT and bone scans. We have found that PET/CT scans offered superior sensitivity, specificity and accuracy than conventional testing and had a significant impact in management decisions.

We have undertaken a large prospective study of PET/CT in children with neurofibromatosis type 1 (NF1) to assess the rate of transformation of plexiform neuromas into malignant tumours and to determine which patients with optic gliomas may benefit from chemotherapy. These scans will enable clinicians to improve treatment choices.

We have completed the world’s largest review of paediatric Lymphoscintigraphy. Our research has identified the different scan patterns, which diagnose congenital lymphoedema. This leads to the earlier diagnosis or exclusion of this condition, allowing more appropriate management decisions.

We were awarded an NHMRC grant (in collaboration with Westmead Hospital) for development of motion correction equipment and software for use in children having PET/CT scans. The aim of this is to reduce the number of infants and children requiring general anaesthesia and sedation for the scans.

Staff profile:
Professor Kate Steinbeck, Medical Foundation Chair in Adolescent Medicine, University of Sydney

New academic chair to boost body of adolescent medicine research

No other animal undergoes as profound a physical and cognitive change during adolescence as humans. During the second decade of life, teenagers are flooded with growth and puberty hormones. Often, they can grow by up to 30 cm and put on up to 30 kg during these years.

Some of these hormone changes are known to influence their physiology. All adolescents develop transient insulin resistance, for example, the female hormone, oestradiol, affects the way some medications are metabolised. Adolescence is also the time when smoking, obesity, mental health issues and risk-taking behaviours often develop.

Yet, unlike paediatric and adult medicine, adolescent medicine is a much newer specialty. There have been relatively few longitudinal studies in this age group and we still know little about how puberty hormones affect health and well-being.

Professor Kate Steinbeck is the University of Sydney’s first chair of adolescent medicine. Her vision is to build up the body of quality research into adolescent medicine and to complement the clinical and research activities that have long been part of the Hospital’s Department of Adolescent Medicine.

“We put so much time and effort into early childhood, but we forget there is another enormous opportunity during puberty and adolescence to alter health trajectories and improve health outcomes into adulthood,” she says.

Professor Steinbeck is undertaking the first truly comprehensive longitudinal study looking at how puberty hormones affect adolescent health and wellbeing.

“Longitudinal studies are very challenging in adolescent medicine, but they can be done. That’s where the evidence gaps are,” she says.

This year, NSW Health announced two Marie Bashir Clinical Research Fellowships which will support research into mental health, risk taking behaviour and chronic illness in adolescents. One project will study the health of young people living out of home, including homeless and incarcerated youth.

Professor Steinbeck’s other interest is how adolescents with chronic conditions are transitioned from paediatric to adult care, and she plans to set up a research clinic to improve self management for young people with chronic illness.
Center for Trauma Care, Prevention, Education and Research (CTCPER)

Group Leaders: Professor Danny Cass, Dr Lawrence Lam

Leading the way in trauma care and research

The Centre for Trauma Care, Prevention, Education and Research (CTCPER) is the core centre for trauma services at the Hospital. Our mission is to provide high quality, evidence based services to children and adolescents injured due to traumatic events; to lead in the prevention of injury among children and adolescents, and to conduct research in trauma care, prevention and education. We also play an important role in training health professionals in trauma-related clinical skills and providing safety information and education to the public.

Research
Our research examines trauma at a number of levels. We conduct quality assurance at the hospital level to ensure that our management of children is as effective and seamless as possible. We are consulted by both government and non-government organisations to provide information and expertise which can be used to change practices in the community. Our work and that of other organisations is devoted to the improvement of childhood safety has led to a significant 10 to 15 per cent reduction of severe trauma rates in NSW.

We are currently researching road and water related injuries as well as spinal injuries in children. For example, we are studying the long-term effects of aquatic immersion on the health, behaviour and well being of children who experienced a near drowning; the cost of trauma; how to prevent children falling from residential buildings, and are conducting an in-depth crash investigation study to determine injury sources and mechanisms among rear seat vehicle occupants.

The NSW Trauma Plan came into effect in March, 2010. Our research into the transfer of paediatric trauma patients provided evidence that supported the paediatric component of this plan.

Nursing Research and Practice Development Unit (NRPDU)

Group Leader: Professor Valerie Wilson

Improving family centred care

The Nursing Research and Practice Development Unit (NRPDU) is undertaking a practice development program which broadly aims to ensure that care delivered at the Hospital meets the needs of patients, families and staff.

Practice development work is progressively being introduced to clinical units throughout the Hospital to encourage staff to explore and improve workplace culture. Activities enable staff to reflect on current practice, identify the need for change and challenge themselves and each other to do better where possible. Our central aim is to achieve improved teamwork and staff satisfaction, sustainable changes in practice, and ultimately improved family centred care.

Research
We are leading the state-wide implementation and evaluation of the Essentials of Care Program (a NSW Health initiative) in paediatrics using a framework of Teamwork-Learning-Change developed by Professor Valerie Wilson. This program of work, which is now occurring in eight units at the Hospital, involves all members of the team. NRPDU is enabling teams to realise an espoused philosophy of family-centred care.

We are leading an international project reviewing the theory underpinning the evaluation of practice development as part of an International Practice Development Colloquium. We are also working in partnership with state and international organisations on a research project involving the practical application of practice development principles and life long learning (REACH).

We are examining the factors that enhance the development of facilitation skills, a vital element in helping individuals and teams to improve the care they deliver and the work environment. We are achieving this by leading and evaluating provision of training and opportunities for development. One such opportunity is a Facilitation in Clinical Practice Program, run annually, that enables health professionals to learn about...
CEPResearch translates scientific research into medical practice and policy by publishing in medical literature as well as the media, medical education, organising conferences and through contributions to major policy committees and national and international scientific bodies.

In addition to translational research, we provide evidence-based literature and other information to researchers, clinicians, authors, journalists and the general public internationally. We continually conduct Cochrane systematic reviews of the literature. We also develop databases of randomised controlled trials, systematic reviews and clinical practice guidelines on paediatric gastroenterology and nutrition, accessible at no cost via the CEPResearch website to clinicians, researchers and the public.

As the translation of research into policy and practice is improved by good quality research training and scientific writing skills, we have designed and implemented a new course for the Sydney Medical School: Scientific Writing for Postgraduates, based on the book she co-authored: Scientific Writing: Easy When You Know How (BMJ Books).

Children’s Hospital at Westmead Clinical School: Discipline of Paediatrics and Child Health, Sydney Medical School, University of Sydney

Group Leader: Professor Kathryn North

Clinical School Overview

The Discipline of Paediatrics and Child Health in the University of Sydney Faculty of Medicine is based within The Children’s Hospital at Westmead Clinical School.

The Faculty of Medicine has recently established six major cross faculty research themes to promote collaboration across disciplines. Associate Professor Cheryl Jones has been appointed as Theme Leader of Reproductive, Maternal and Child Health. Professor Louise Baur has been appointed as Theme Leader of Obesity, Diabetes and Cardiovascular Disease. The Royal Australasian College of Physicians has established a Specialist Advisory Committee in Academic Medicine and Dr Patrina Caldwell has been appointed as the Paediatric representative.

Our staff are leaders in medical education and research.

Each year we administer and support more than 350 medical students as they undertake their paediatric rotation at The Children’s Hospital at Westmead, as well as more than 80 postgraduate students undertaking Masters and PhDs at the Hospital.

Our staff play a significant role in creating an inspiring environment within which students gain the relevant high quality education and experiences that includes the option to embark upon a clinical research career.

Our senior academics lead successful national and international translational research programs. Our research is underpinned by questions that arise in the clinical setting and is aimed at promoting excellence in the care of our patients and improving health outcomes for children and adolescents nationally and internationally.

Our activities include investigating evidence-based methods of information delivery to students and medical professionals; participating in curriculum development for medical students; coordinating resources and offering research projects that are contributing at the forefront of their field of research.

The above activities include the Kim Oates Australian Paediatric Simulation Centre, which provides hands-on clinical skills training to students and health professionals at all levels of training. The University has provided seed funding for the Australian Children’s Clinical Trials Centre, and has joined with the Hospital to provide a Partnership in Diploma in Child Health and International Postgraduate Paediatric Certificate.
Snapshot: Nursing Research and Practice Development Unit (NRPDU)

“Our research has shown the tangible substance of the beads. The key is that they assist families to come to terms with the conditions and overcome the trauma of treatment.”
– Professor Val Wilson, Head, Nursing Research & Practice Development Unit

Beads help families tell a story from the heart

Jordan Mildenhall was rushed to hospital at just 16 days old. The serious heart condition with which she was diagnosed led to two admissions to The Children’s Hospital at Westmead, heart surgery and a long stay in intensive care.

For her parents, Jared and Sarah, watching the daily suffering of their fourth child as she underwent a raft of painful hospital procedures was devastating. Then one of the fathers in the ward suggested they enrol in the Heart Beads Program.

Initially developed overseas to help children through treatment for cancer, the program is designed to give children and their families tangible symbols to document and honour their long and difficult journey to recovery.

Small porcelain shapes of varying colours and patterns are presented to children – or their families if the child is too young – to represent each procedure that they endure. Their growing collection of beads enables them to put together a narrative of their hospital stay.

“The Heart Beads Program enables families and children to document the child’s experiences in a unique and child-friendly way. It adds a positive dimension to their treatment and ultimately reduces the stress involved in their hospital admission,” says Professor Valerie Wilson, Head of the Nursing Research and Practice Development Unit.

A paper accepted for publication in the Journal of Clinical Nursing found the Heart Beads appeared to allow both parents and children to create meaning from the experiences with which they were confronted.

For the Mildenhall family, the beads became central to their ability to cope with Jordan’s illness.

“It meant you got something to signify the pain your child was going through, and the pain you were going through with her,” says Sarah.

“For Jared especially, it signified a tangible thing that you were able to grab onto and see.”

During her two stays in hospital, Jordan received 81 heart beads – 12 in one terrible day. Now she is a healthy two year old, her parents have kept her heart beads as a reminder to her and the other children of what she went through as a baby.

“I swear by them. They give parents going through pain something to show for the big milestones. We were blessed,” says Sarah.
Research and support staff

Research Office

The Research Office is located in the Kerry Packer Building of The Children’s Hospital at Westmead and supports research through the provision of strategic initiatives, grants, scholarships, laboratory, ethics and governance, clinical trials, fundraising, intellectual property and commercialisation.

Director
A/Prof Chris Cowell

Research and Development Manager
Karyn Joyner (from September 2009)

Executive Support Officer
Amelia Hill

Grants and Scholarships Officer
Lyndsey Bray

Accountant
Wesley Beh (to January 2010)
Priya Viswakula (from March 2010)

Research Governance Managers
Carolyn Casey
James Cokayne

Ethics Manager
Eleanor Thackray
Karen Steinhoff - maternity relief (from February 2010)

Ethics Administration Assistant
Jessica Moller

Clinical Trials Project Coordinator
Dr Kimberley Lilischkis
Lucia Smith

Clinical Trials Pharmacist
Pathma Joseph

Statistician
Dr Federica Barzi
Dr Liz Barnes - Maternity relief (from March 2010)

Transgenic Facility Manager
Rebecca Reilly

Senior Technical Officer
Karen Knight

Animal Technicians
Heidi Leshmann
Kevin Kerr
Veronica Pollero

Engineering Manager
Stephen Gorrey

Advanced Microscopist & Imaging Specialist
Dr Laurence Cantrill

Electron Microscopist
Dr Marko Nykanen (to May 2010)

Laboratory Manager
Matthew Laver

Laboratory Officer
Trish McGregor

Laboratory Assistant
Deidre Shiel

Facility Support Officer
Anne Sutherland

IT Support Officer
Imran Hussain
Allied Health

Audiology
Rosemary Douglas - Head Audiologist

Kids Health
Candace Douglass - Department Head

Dietetics
Prue Watson - Acting Manager
Susie Burell - Obesity Service Dietitian
Kerryn Chisholm - Obesity Service Dietitian
Christie Graham - CF Dietitian
Rebecca Fisher - Oncology BMT Dietitian
Kathryn Webb - Oncology Dietitian
Maggie Aitken - Renal Dietitian
Katie Marks - Renal Dietitian / Gastroenterology

Dietitian
Barbara Dennison - Allergy Dietitian
Susan Thompson - Senior Dietitian, Genetic Metabolic Disorders Service

Occupational Therapy
Margaret Wallen - Senior Occupational Therapist
Prof Anita Bundy - Honorary Appointment
Paula Bray - Occupational Therapist

Pharmacy
Penny Thornton - Pharmacy Services Manager
Peter Barclay - Deputy Director of Pharmacy
Pathma Moodley - Clinical Trials and Drug Information Senior Pharmacist
Joyce Liew - Clinical Pharmacist

Physiotherapy
Jennifer Follett - Department Head
Kerry West - Deputy Head
Verity Pacey - Senior Physiotherapist
Kelly Evans - Senior Physiotherapist
Bronwyn Thomas - Senior Physiotherapist

Rehabilitation
Jan Hancock - Senior Physiotherapist, Rehabilitation
Alison Elliott - Physiotherapist, Cystic Fibrosis
Jenny Wu - Senior Physiotherapist, Cerebral Palsy
Karen Bau - Senior Physiotherapist, Cerebral Palsy
Alison Chivers - Physiotherapist, Talipes

Students
Verity Pacey - PhD
Kelly Evans - Masters
Anna Middleton - PhD

Psychological Medicine Psychologists
Dr Sloane Madden - Department Head
Dr David Dossetor - Area Director for Mental Health

Dr Kasia Koslowska - Child Psychiatrist
Dr Michael Bowden - Child Psychiatrist
Dr Catherine Wiltshire - Child Psychiatrist
Dr Angela Dixon - Senior Clinical Psychologist
Dr Karen Hancock - Research Psychologist
Karen Munro - Senior Clinical Psychologist
Siew Koo - Clinical Psychologist
Dr Michelle Wong - Clinical Psychologist
Jane Miskovic - Research Psychologist
Cassandra Hainsworth - Research Psychologist

Anaesthesia Department

Staff
Dr David Baines - Department Head
Dr Neil Street - Deputy Head
Dr Stephanie Aplin - Consultant Anaesthetist
Dr Jenny Chien - Consultant Anaesthetist
Dr Michael Cooper - Consultant Anaesthetist
Dr Jonathan De Lima - Consultant Anaesthetist
Dr Peter Gibson - Consultant Anaesthetist
Dr Sue Hale - Consultant Anaesthetist
Dr Donald Innes - Consultant Anaesthetist
Dr Ramanie Jayaweera - Consultant Anaesthetist
Dr Sarah Johnston - Consultant Anaesthetist
Dr David Kincingston - Consultant Anaesthetist
Dr Mark Lovell - Consultant Anaesthetist
Dr Ian Miles - Consultant Anaesthetist
Dr David Murrell - Consultant Anaesthetist
Dr Michele O’Brien - Consultant Anaesthetist
Dr Kate Pennington - Consultant Anaesthetist
Dr Lian Pfitzner - Consultant Anaesthetist
Dr Kristen Schwager - Consultant Anaesthetist
Dr Ian Sherratt - Consultant Anaesthetist
Dr Rasa Venclovas - Consultant Anaesthetist
Dr Harry Wark - Consultant Anaesthetist
Dr Andrew Weatherall - Consultant Anaesthetist
Dr Sally Wharton - Consultant Anaesthetist
Dr Don Hannah - Consultant Anaesthetist
Dr James MacDonald - Consultant Anaesthetist
Dr Jane MacDonald - Consultant Anaesthetist
Dr Margaret Perry - Consultant Anaesthetist
Dr Justin Skowno - Consultant Anaesthetist

Students
Roumel Valentin
Christine Duong

Australian Paediatric Surveillance Unit

Staff
Prof Elizabeth Elliott - Director
Dr Yvonne Zurynski - Deputy Director
Dr David Lester-Smith - Research Officer
Research and support staff

Dr Katie Reeve - Research Officer
Dr Elizabeth Davey - Research Fellow
Dr Nicola Benwell - Research Officer
Dr Monica Lahra - Research Fellow
Greta Ridley - Research Consultant
Leanne Vidler - Research Coordinator PAEDS
Nicole McKay - Data Manager
Karen Pattinson - Office Coordinator
Ingrid Charters - Administration Officer
Trudy Butlin - Administration Officer
Sarah Srikanthan - Publications Project Officer
Dr Diana Thomas - Scientific Director, CEBPGAN

Students
Michael Smith - Summer Scholarship
Elizabeth Peardon - Research Fellow/PhD
Nicola Benwell - Honours
Kate Larking - Honours
Matilda Anderson - Honours
James Fitzpatrick - PhD
Lucy Attwood - Honours

Centre for Kidney Research
Clinical and Laboratory

Staff
Prof Jonathan Craig - Head, Clinical Research
A/Prof Stephen Alexander - Head, Laboratory Research
Dr Elisabeth Hodson - Staff Specialist, Nephrology/Co-chair Medical Programs
Dr David Andresen - Medical Microbiologist and Epidemiologist
Dr Patrina Caldwell - Research Staff Specialist Nephrology
Denise Campbell - Senior Project Officer
Sonia Crampton - Data Manager
Dr Anne Durkan - Staff Specialist, Nephrology
Dr Hasantha Gunasekera - Staff Specialist, General Medicine
Sana Hamilton - Trials Coordinator
Gail Higgins - Trials Search Coordinator
Dr Martin Howell - Research Officer
Dr Min Hu - Research Scientist
Dr Michelle Irving - Senior Research Officer
Rachael Kearns - Research Officer
Marianne Kerr - Trials Recruitment Officer Data Manager
Anh Kieu - Research Assistant
Pamela Lopez Vargas - Project Officer
Ruth Mitchell - Trials Search Coordinator
A/Prof Paul Roy - Senior Clinical Researcher
Dr Giovanni Strippoli - Honorary Research Fellow
Dr Premala Sureshkumar - Research Fellow

Sean Taylor - Project Manager
Dr Allison Tong - Research Officer
Edwina Vale - Data Manager
Dr Angela Webster - Senior Research Fellow
Dr Gabrielle Williams - Research Only Lecturer
Narelle Williams - Research Nurse
Rita Williams - Senior Aboriginal Health Education Officer
Narelle Willis - Coordinator, Cochrane Renal Group
Dr Germaine Wong - Senior Research Fellow
Nicola YuKasin - Research Officer
Dr Geoff Zhang - Senior Hospital Scientist
Dr Yuan Min Wang - Senior Research Officer
Dr Min Hu - Research Officer
Dr Debbie Watson - Research Assistant
Jian-Heng Zhou - Research Assistant
Sandra Puckeridge - Office Manager
Tamara Borysko - Administration Officer
Leslee Edwards - Administration Officer
Venishra Naidoo - Administration Officer

Students
Dr Miriam Codarini - PhD
Dr Sukanya De - PhD
Dr Aniruddh Deshpande - PhD
Dr Richard McGee - PhD
Dr Angie Morrow - PhD
Dr Yashwant Sinha - PhD
Dr Della Yamold - PhD
Tania Polhill - PhD

Centre for Perinatal Infection Research

Staff
A/Prof Cheryl Jones - Laboratory Head
Dr Marian Fernandez - Postdoctoral Scientist
Rose White - Senior Research Assistant
Diane Hanlon - Administrative Assistant

Students
Eddy Hassan - PhD
Franz Puttur - PhD
Elise Tonna - Honours Medical Science (Infection and Immunology)

Centre for Trauma Care, Prevention, Education and Research

Staff
Prof Danny Cass - Department Head
Dr Lawrence Lam - Scientific Director
Frank Ross - Senior Research Associate
Fiona Fahy - Senior Research Associate
Patricia Manglick - Senior Data Manager
Research and support staff

Children's Cancer Research Unit

Staff
A/Prof Jennifer Byrne - Acting Unit Head
Dr Geraldine O’Neill - Group Leader
Dr Daniel Catchpoole - Group Leader
Dr Loretta Lau - Group Leader
Dr Yuyan Chen - Research Officer
Dr Justin Lees - Research Officer
Dr Kylie Turner - Research Officer
Dr Andre Paul - Research Officer
Dr Albert Chetcuti - Project Officer
Dr Belinda Kramer - Research Officer
Jayne Hardy - Research Assistant
Peta Bradbury - Research Assistant
Maha Mahmassani - Research Assistant
Jaime Baquiran - Research Assistant
Guy Nelmes - Research Assistant
Rebecca Dagg - Research Assistant
Jessica Hyman - Research Assistant
Nicolle Mackie - Technical Officer
Kerrie Jones - Tumour Bank Database Administrator
Nicholas Ho - Computational Biologist
Juliake Palmer - Clinical Nurse Consultant
Radhika Singh - Quality Officer
Hamid Ghaus - Research Assistant (external)
Amanda Skulte - Research Assistant
Janett Clarkson - Research & Development Manager
Vanita D’Souza - Research Support Officer

Students
Keerthi Thamotharampillai - PhD
Austin Della Franca - PhD
Hamideh Shahheydari - PhD
Nuruliza Rozlan - PhD
Le Myo Thwe (Lesley) - PhD
Nancy Martin - PhD
Natalie Pfund - MBBS
Cuc Bach - PhD
Jessie Zhong - PhD
Karman Pathmanandavel - MBBS
Claire Van Der Helm - Dutch Pharmacy
Ahmed Al Oqaily - PhD (External)
Franco Ubaudi - PhD (External)
Tony Huynh - BSc Honours
Linda Gomes - MSc (external)

Children’s Hospital Burns Research Institute / Wound Healing Laboratory

Staff
A/Prof Andrew Holland - Director
A/Prof John Harvey - Department Head

Dr Rachael Z Murray - Department Head, Wound Healing Laboratory
Dr Heather Medbury - Senior Scientist
Dr Ann Guiffre - Senior Scientist
Dr Queenie Chan - Burns Fellow
Dr Erik R. La Hei - Surgeon
Dr Peter Hayward - Surgeon
Dr John Vandervord - Plastic & Reconstructive Surgeon
Dr Robert Gates - Plastic Surgeon
Nazi Lei - Research Assistant
Bianca Richards - Research Assistant
Kelly Veale - Research Assistant

Student
Carolin Offenhauser

Children’s Hospital Educational Research Institute

Staff
Dr Belinda Barton - Department Head
Aparajita Jita - Research Psychologist
Dr Richard Webster - Paediatric Neurologist & Researcher
Lisa Brice - Clinical Psychologist
Michael Gascoigne - Doctorate of Psychology
David Fitzsimons - PhD/Cleft Palate Speech Pathologist
Jennifer Lorenzo - PhD/Psychologist

Children’s Hospital Institute of Sports Medicine

Staff
Dr Robert Parker - Department Head/Senior Paediatric Exercise Physiologist
Dr Carolyn Broderick - Staff Specialist Paediatric Sports Medicine
Dr Damien McKay - Chief Resident Medical Officer; Paediatric Sports Medicine Fellow
Dr Gary Browne - Senior Staff Specialist Paediatric Sports Medicine
Nancy van Doorn - Paediatric Exercise Physiologist

CHW Clinical School: Discipline of Paediatrics and Child Health

Staff
Prof Kathryn North - Associate Dean
Prof Louise Baur - Deputy Associate Dean
A/Prof Cheryl Jones - Sub Dean Research
Dr Russell Dale - Sub Dean Postgraduate Studies and Postgraduate Coordinator
Research and support staff

Department of Allergy and Immunology

Staff
A/Prof Alyson Kakakios - Department Head
Dr Melanie Wong - Director of the Immunology Laboratory
A/Prof Dianne Campbell - Staff Specialist
Dr Preeti Joshi - Staff Specialist
Dr Sam Mehr - Locum Staff Specialist/Research Fellow
Dr Paul Turner - Immunology Fellow
Dr Andrew Williams - Principal Scientist/Immunology Laboratory Manager

Developmental Cognitive Neuropsychology Research Unit

Staff
Ruth Brunsdon - Senior Clinical Neuropsychologist
Suzanne Benson - Senior Clinical Psychologist & Clinical Neuropsychologist
Ellen Northcott - Clinical Neuropsychologist
Sara Coombes - Senior Clinical Neuropsychologist
Signy Wegener - Clinical Neuropsychologist
Alex Wilson - Research Assistant
Bronwyn Coward - Research Assistant
Pam Joy - Senior Clinical Neuropsychologist
Jane Cramsie - Clinical Neuropsychologist
Melanie Porter - Honorary Clinical Neuropsychologist
Louise Parry - Clinical Neuropsychologist
Graham C Menzies

Students
Lauren Gillett
Farah Budhani

Eating Disorder Service
Departments of Psychological Medicine and Adolescent Medicine

Staff
Dr Sloane Madden – Team Leader, Senior Staff Specialist
A/Prof Michael Kohn – Team Leader, Senior Staff Specialist
Dr David Dossetor - Area Director for Mental Health
Jane Miskovic - Eating Disorders Research Coordinator/DCP
Andrew Wallis - Senior Social Worker/PhD
Colleen Alford - Senior Social Worker
Aimee Hanson - Clinical Psychologist
Joanne Titerton - Clinical Nurse Consultant

Department of Adolescent Medicine

Staff
Clinical A/Prof Susan Towns - Head of Adolescent Medical Unit
Prof Kate Steinbeck - Head of Academic Department of Adolescent Medicine
A/Prof Michael Kohn - Head of Research Program, Senior Staff Specialist
Prof David Bennett - Deputy Head, Senior Staff Specialist
Helen Bibby - Clinical Psychologist/Researcher
Ronald Hoffman - Head, Psychosocial Team
Andrew Wallis - Head, Family Therapy Team
Susan Sampson - Clinical Nurse Consultant
Dr Bronwyn Milne - Staff Specialist, SAMY
Popi Zappia - Individual and Family Therapist, Teen-Link & SAMY
A/Prof Simon Clarke - Honorary Staff Specialist, AMU

Department of Allergy and Immunology

Staff
A/Prof Alyson Kakakios - Department Head
Dr Melanie Wong - Director of the Immunology Laboratory
A/Prof Dianne Campbell - Staff Specialist
Dr Preeti Joshi - Staff Specialist
Dr Sam Mehr - Locum Staff Specialist/Research Fellow
Dr Paul Turner - Immunology Fellow
Dr Andrew Williams - Principal Scientist/Immunology Laboratory Manager

Developmental Cognitive Neuropsychology Research Unit

Staff
Ruth Brunsdon - Senior Clinical Neuropsychologist
Suzanne Benson - Senior Clinical Psychologist & Clinical Neuropsychologist
Ellen Northcott - Clinical Neuropsychologist
Sara Coombes - Senior Clinical Neuropsychologist
Signy Wegener - Clinical Neuropsychologist
Alex Wilson - Research Assistant
Bronwyn Coward - Research Assistant
Pam Joy - Senior Clinical Neuropsychologist
Jane Cramsie - Clinical Neuropsychologist
Melanie Porter - Honorary Clinical Neuropsychologist
Louise Parry - Clinical Neuropsychologist
Graham C Menzies

Students
Lauren Gillett
Farah Budhani

Eating Disorder Service
Departments of Psychological Medicine and Adolescent Medicine

Staff
Dr Sloane Madden – Team Leader, Senior Staff Specialist
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Dr David Dossetor - Area Director for Mental Health
Jane Miskovic - Eating Disorders Research Coordinator/DCP
Andrew Wallis - Senior Social Worker/PhD
Colleen Alford - Senior Social Worker
Aimee Hanson - Clinical Psychologist
Joanne Titerton - Clinical Nurse Consultant
Research and support staff

Gene Therapy Research Unit
Children's Medical Research Institute and The Children's Hospital at Westmead (Joint Unit)

Staff
Prof Ian Alexander - Unit Head
Dr Sharon Cunningham - Research Fellow
Dr Julie Curtin - Clinical Researcher
Dr Samantha Ginn - Noel Dowling Research Fellow
Dr Claus Hallwirth - Research Fellow
Margot Latham - Research Administrator
Sophia Liao - Research Assistant
Dr Grant Logan - Research Fellow
Dr Christine Smyth - Senior Research Officer
Afroditi Spinoulas - Research Assistant
Maolin Zheng - Senior Research Assistant

Students
Gustavo Alencastro - PhD
Rachel Botting - Honours
Allison Dane - PhD
Claire Deakin - PhD
Cindy Kok - PhD
Susan Siew PhD

Emergency Department

Staff
Dr Mary McCaskill - Co-Chair Ambulatory & Emergency
Leonnie Dawson - Nurse Manager & Co-Head
Prof Gary Browne - Head Academic Emergency Medicine
Dr Nicholas Cheng - Chair ED Research Committee

Human Genome Research Program

Genetic Metabolic Disorders Research Group (including the NSW Centre for Rett Syndrome Research)
Prof John Christodoulou - Director, Western Sydney Genetics Program

Biochemical Genetics and Newborn Screening Research Group
Prof Bridget Wilcken - Director
Dr Kevin Carpenter - Head, Biochemical Genetics
A/Prof Veronica Wiley - Head, Newborn Screening
Tiffany Wotton - Hospital Scientist

Students
Ahmad Al-Odaib - MPhil

Eye and Developmental Genetics Research Group, Western Sydney Genetics Program, CHW

Eye Genetics Research Group, Embryology Unit, CMRI
Dr Robyn Jamieson - Department Head
Dr Yongjuan Chen - Sir Norman Gregg Postdoctoral Fellow
Dr Linda Weaving - CJ Martin Postdoctoral Fellow
Rebecca Storen - Research Assistant

Students
Wan Yi Ng - PhD
Rebecca Greenlees - Honours
Saira Mohamed Yousoof - PhD

Marfan Syndrome Research Group
Dr Lesley Adès - Department Head
A/Prof Bruce Bennetts - Department Head, Molecular Genetics
Dr Andrew Biggin - Honorary Research Fellow
Katherine J Holman - Hospital Scientist
Thet Gayagay - Hospital Scientist

Students
Kate Sullivan - PhD

Skeletal and Lysosomal Disorders Research Group (collaborating with the Centres for Children's Bone Health and Genetic Innovative Therapies)
Prof David Silience - Department Head
Dr Louise Tofts - Fellow in Musculoskeletal Rehabilitation

Students
Ahmad Alodib - MPhil
Roksana Armani - PhD
Elisa Bettella - PhD
Gladys Ho - PhD
Minal Menezes - PhD
Vidya Nelaturi - PhD
Dr Margaret Perry - PhD
Katrina Slater - MPhil

Dr Wendy Gold - Postdoctoral Scientist
Dr Lisa Riley - Postdoctoral Scientist
Dr Xing Zhang Tong - Postdoctoral Scientist
Dr Sarah Williamson - Postdoctoral Scientist
Gladys Ho - Research Scientist

Students
Ahmad Alodib - MPhil
Roksana Armani - PhD
Elisa Bettella - PhD
Gladys Ho - PhD
Minal Menezes - PhD
Vidya Nelaturi - PhD
Dr Margaret Perry - PhD
Katrina Slater - MPhil

Biochemical Genetics and Newborn Screening Research Group
Prof Bridget Wilcken - Director
Dr Kevin Carpenter - Head, Biochemical Genetics
A/Prof Veronica Wiley - Head, Newborn Screening
Tiffany Wotton - Hospital Scientist

Students
Ahmad Al-Odaib - MPhil

Eye and Developmental Genetics Research Group, Western Sydney Genetics Program, CHW

Eye Genetics Research Group, Embryology Unit, CMRI
Dr Robyn Jamieson - Department Head
Dr Yongjuan Chen - Sir Norman Gregg Postdoctoral Fellow
Dr Linda Weaving - CJ Martin Postdoctoral Fellow
Rebecca Storen - Research Assistant

Students
Wan Yi Ng - PhD
Rebecca Greenlees - Honours
Saira Mohamed Yousoof - PhD

Marfan Syndrome Research Group
Dr Lesley Adès - Department Head
A/Prof Bruce Bennetts - Department Head, Molecular Genetics
Dr Andrew Biggin - Honorary Research Fellow
Katherine J Holman - Hospital Scientist
Thet Gayagay - Hospital Scientist

Students
Kate Sullivan - PhD

Skeletal and Lysosomal Disorders Research Group (collaborating with the Centres for Children's Bone Health and Genetic Innovative Therapies)
Prof David Silience - Department Head
Dr Louise Tofts - Fellow in Musculoskeletal Rehabilitation

Students
Ahmad Alodib - MPhil
Roksana Armani - PhD
Elisa Bettella - PhD
Gladys Ho - PhD
Minal Menezes - PhD
Vidya Nelaturi - PhD
Dr Margaret Perry - PhD
Katrina Slater - MPhil

Biochemical Genetics and Newborn Screening Research Group
Prof Bridget Wilcken - Director
Dr Kevin Carpenter - Head, Biochemical Genetics
A/Prof Veronica Wiley - Head, Newborn Screening
Tiffany Wotton - Hospital Scientist

Students
Ahmad Al-Odaib - MPhil

Eye and Developmental Genetics Research Group, Western Sydney Genetics Program, CHW

Eye Genetics Research Group, Embryology Unit, CMRI
Dr Robyn Jamieson - Department Head
Dr Yongjuan Chen - Sir Norman Gregg Postdoctoral Fellow
Dr Linda Weaving - CJ Martin Postdoctoral Fellow
Rebecca Storen - Research Assistant

Students
Wan Yi Ng - PhD
Rebecca Greenlees - Honours
Saira Mohamed Yousoof - PhD

Marfan Syndrome Research Group
Dr Lesley Adès - Department Head
A/Prof Bruce Bennetts - Department Head, Molecular Genetics
Dr Andrew Biggin - Honorary Research Fellow
Katherine J Holman - Hospital Scientist
Thet Gayagay - Hospital Scientist

Students
Kate Sullivan - PhD

Skeletal and Lysosomal Disorders Research Group (collaborating with the Centres for Children's Bone Health and Genetic Innovative Therapies)
Prof David Silience - Department Head
Dr Louise Tofts - Fellow in Musculoskeletal Rehabilitation

Students
Ahmad Alodib - MPhil
Roksana Armani - PhD
Elisa Bettella - PhD
Gladys Ho - PhD
Minal Menezes - PhD
Vidya Nelaturi - PhD
Dr Margaret Perry - PhD
Katrina Slater - MPhil
Research and support staff

Dr Michel Tchan - Fellow in Medical Genetics (Genetic Medicine)
Kerry Devine - Genetic Therapies Coordinator
Lynne Foxall - Bisphosphonate Therapies Research Coordinator

Clinical Genetics Department
Dr Felicity Collins - Department Head

Students
Ron Cheung
Heidi Quinn

Institute for Neuroscience and Muscle Research

Staff
Prof Kathryn North - Department Head
Dr Nan Yang - Team Leader / Senior Hospital Scientist
Dr Peter Houweling - Research Officer
Dr Jane Seto - Research Officer
Fiona Zheng - Research Assistant
Dr Sandra Cooper - Team Leader / Senior Hospital Scientist
Joanne Hawkes - Research Assistant
Dr Nigel Clarke - Co-Team Leader / Clinical Geneticist
Dr Bilijana Ilkovski - Co-Team Leader / Senior Research Officer
Dr Kate Quinlan - CJ Martin Fellow
Dr Jonathan Payne - Team Leader / Neuropsychologist
Jennifer Lorenzo - Educational Psychologist/PhD
Shelley Robertson - Research Assistant
Dr Richard Webster - Neurologist
Natalie Pride - Research Assistant
Dr Simone Ardern-Holmes - Neurogenetics Fellow
A/Prof Joshua Burns - Team Leader / Senior Research Fellow
Stephanie Wicks - Clinical Trials Evaluator
Dr Manoj Menezes - Fellow
Dr Emily Oates - Fellow/PhD
Dr Simone Ardern-Holmes - Fellow
Dr Russell Dale - Co-Team Leader / Senior Lecturer / Fellow
Dr Fabienne Brilot-Turville - Co-Team Leader / Senior Research Officer
Vera Merheb - Research Assistant
A/Prof Brian Owler - Team Leader / Neurologist
Dr Lucy Wang - Research Officer
Natalie Gabrael - Clinical Trials Coordinator
Ellie Faramus - Clinical Trials Coordinator

Students
Dr Mimi Berman - PhD
Monkol Lek - PhD
Fleur Garton - PhD
Marshall Hogarth - PhD
Angela Chen - PhD
Frances Evesson - PhD
Frances Lemckert - Masters
Nancy Mokbel - PhD
Dr Ana Domazetovska - MBBS Honours
Michaela Kreissl - Overseas Masters
Jenny Tran - MBBS Honours
Leigh Waddell - PhD / Laboratory Data Coordinator
David Fitzsimons - PhD
Kristy Rose - PhD / Clinical Trials Coordinator
Paula Bray - PhD
Alice Ding - Honours
Dr Sekhar Pillai - Masters
Dr Esther Tantsis - Neurology Fellow/Masters
Dr Sekhar Pillai - Advanced Trainee, PhD
Dr Jehan Sulieiman - Advanced Trainee, Masters
Dan Daly - BSc, Honours
Katie Yin - BSc, Honours

Institute of Endocrinology and Diabetes

Staff
A/Prof Chris Cowell - Director
A/Prof Kim Donaghue - Section Head of Diabetes Services & Diabetes Complications Assessment Service
A/Prof Geoffrey R Ambler - Section Head of Clinical Endocrinology and Growth, Information Systems and Technology
Dr Neville J Howard - Senior Staff Specialist, Principal Investigator, TRIGR (Australia)
A/Prof Maria Craig - Staff Specialist
Prof Martin Silink - Senior Staff Specialist
Dr Craig Munns - Senior Staff Specialist
Dr Shubha Srinivasan - Staff Specialist
Dr Ann Maguire - Staff Specialist
Dr Sarah Garnett - Clinical Research Fellow
Jim Minchenko - Research Scientist, Endocrine Laboratory
Alison Pryke - Research Assistant, Diabetes Complications & Assessment
Ros Bongiorno - TRIGR Nutrition Coordinator
Tracey Jopling - Research Assistant, Diabetes Complications & Assessment
Jackie Chateau - TRIGR Research Nurse Coordinator
Margaret Lloyd - CNC Diabetes Prevention Research Nurse Coordinator
Lynne Foxall - RN Research Trial Coordinator
Lori Hopley - Nutrition and Dietetics, Research Assistant
Megan Dunkley - Research Assistant
Dr Sukanya De - Research Officer
Rebecca Cook - Nutrition and Dietetics, Research Assistant
Catherine Kay - Business Manager
Albert Chan - Clinical Info and Systems Manager/Statistician
Jenny Lee - Manager, Endocrine Laboratory
Oksana Markowsch - Scientist, Endocrine Laboratory
Dr Yoom Hi Cho - Clinical Fellow
Darna Bradford - Scientist, Endocrine Laboratory
Liz Lawrie - CNC Endo-testing Unit
Kelly Winning - RN Endo-testing Unit
Janine Cusumano - CNS Diabetes Complications & Assessment Coordinator
Mary Maquade - CNC Bone Services Nurse Coordinator
Nuala Harkin - Nurse Practitioner
Rachel Hayes - Senior Diabetes Dietitian

Students
Dr Kim Ramjan - Research Fellow
Dr Paul Benitez-Aguirre - Research Fellow
Dr Myra Poon - Research Fellow
Charmaine Tam - PhD candidate
Anna Pham - Dietitian/PhD

James Fairfax Institute of Paediatric Nutrition/Gastroenterology

Staff
Prof Kevin Gaskin - Department Head
Dr Caron Blumenthal - Senior Research Dietitian
Cheryl Frazer - Personal Assistant/Administration Officer

Students
Dorothea Stark - PhD
Sharon Youde - M Sci (Med)

Kids Heart Research

Staff
A/Prof David Winlaw - Department Head
Dr Tanya Butler - Senior Scientist
Gillian Blue - Genetic Counsellor
Joanne Hawkes - Animal Technician
Gina Walizada - Research Assistant
Jody Middlemiss - Administrative Coordinator
Cathleen Kuznesoff - Administrative Coordinator

Kids Rehab

Staff
Dr Stephen O'Flaherty - Department Head
Dr Angie Morrow - Staff Specialist, Head of Brain Injury Service
Suzanne Benson - Senior Clinical Psychologist
Mary-Clare Waugh - Head of CP and Movement Disorder Service
Lynne McCartney - Clinical Nurse Consultant
Dr Simon Paget - Rehabilitation Fellow
Louise Tofts - Locum Staff Specialist
Jennifer Lewis - Physiotherapist
Tamis Pin - Senior Physiotherapist
Deb Hughes - Case Manager
Helene Chew - Coordinator Brain Injury Service

National Centre for Immunisation Research and Surveillance of Vaccine Preventable Diseases

Staff
Prof Peter McIntyre - Director
Prof Robert Booy - Head, Clinical Research
Prof Raina MacIntyre - Senior Principal Research Fellow
Dr Kristine Macartney - Deputy Director, Government Programs
Robert Menzies - Deputy Director, Surveillance
Dr Jane Jelfs - Manager Policy Support
Dr Julie Leask - Manager Social Research
Dr Aditi Dey - Acting/Manager Surveillance
Dr Leon Heron - Manager Clinical Trials
Dr Glenda Lawrence - Senior Research Fellow
Dr Nicholas Wood - Senior Clinical Research Fellow
Dr Clayton Chiu - Senior Clinical Research Fellow
Dr Yeqin Zuo - Senior Clinical Research Fellow
Dr Gulam Khandaker - Clinical Research Fellow
Dr Danforn Lim - Clinical Research Fellow
Dr Alex Dierig - Clinical Research Fellow
Dr Helen Quinn - Research Fellow
Brynley Hull - Epidemiologist
Research and support staff

Telphia Joseph - National Indigenous Immunisation Coordinator
Dr Iman Ridda - Immunisation Research Coordinator/ Senior Research Officer
Han Wang - Statistician/Data Manager
Dr Sanjay Jayasinghe - Senior Policy Officer
Dr Spring Cooper - Senior Research Officer
Dr Deepika Mahajan - Senior Research Officer
Dr Melina Georgousakis - Research Officer
Mamta Porwal - Research Assistant
Kerrie Wiley - Research Assistant
Amanda Edkins - Research Assistant
Swati Ghotane - Research Assistant
Anita Heywood - Research Assistant
Dr Kevin Yin - Research Assistant
Maria Chow - Research Assistant
Linda Hueston - Scientific Officer (Laboratory Studies)
Elizabeth Clarke - Research Nurse
Rose Joyce - Research Nurse
Jennifer Murphy - Research Nurse
Laura Rost - Research Nurse
Carol Shineberg - Research Nurse
Pamela Cheung - Research Nurse
Elizabeth Deegan - Research Nurse
Edwina Jacobs - Research Nurse
Camille Lang - Research Nurse
Lisa Chalmers - Research Nurse
Leanne Vidler - PAEDS Coordinator
Catherine King - Information Manager
Edward Jacyna - Assistant Librarian
Donna Armstrong - Editing and Publications Officer
Danielle Grant - Communications Officer
Karyn Phillips - Business Manager
Lynda Beaumont - Personal Assistant
Danielle Marchant - Personal Assistant
Nicole Jacobs - Personal Assistant
Joanne Perkins - Senior Administrative Officer
Lyn Benfield - Senior Project Administration Officer

Students
Dr Nicholas Wood - PhD
Anita Heywood - PhD
Robert Menzies - PhD
Dr Katherine Hale - PhD
Dr Iman Ridda - PhD
Catherine King - PhD
Dr Kevin Jiehui Yin - PhD
Telphia Joseph - MPhil
Sumalathaa Krishnamoorthy - MPH (Hons)
Swati Ghotane - MPH
Anthea Katelaris - MBBS

Nuclear Medicine

Staff
Prof Robert Howman-Giles - Department Head
Prof Roger Uren - Physician
Dr Kevin London - Clinical Fellow
A/Prof Vijay Kumar - Principle Scientist, Radiopharmacy
Dilip Bodetti - Radiopharmacy
Julie Briody - BMD Scientific Officer
Justine Trpezanovski - Chief Technologist
Theo Kitsos - Deputy Chief Technologist

Nursing Research & Practice Development Unit

Staff
Prof Valerie Wilson - Director
Margaret Kelly - Clinical Nurse Consultant/ PhD
Dr Sarah Redshaw - Senior Researcher
Chris White - REACH Project Coordinator
Rachel Primrose - Program Manager (TLC/EOC and CEC CLP)
Claudia Green - Program Manager (TLC/EOC)
Anne Bassett - Administrative Officer

Students
Amy Barker - Honours Research
Christine Jorgensen - Honours Research
Ruth Mychael - Honours Research
Elaine McCall - Professional Doctorate
Pippa Mitchell - Masters

Obesity Research Group

Staff
Prof Louise Baur - Department Head
Gillian Brown - Administrative Officer
Dr Paola Espinel - Project Officer
Kelly Kornman - Research Assistant
Anthea Lee - Research Assistant
Binh Nguyen - Research Assistant

Students
Genevieve Dwyer - PhD
Vanessa Shrewsbury - PhD
Charmaine Tam - PhD

Oncology Department

Staff
Dr Luciano Dalla-Pozza - Department Head
Dr Geoff McCowage - Senior Staff Specialist
Dr Michael Stevens - Senior Staff Specialist
Dr Mary Bergin - Senior Staff Specialist
Prof Stewart Kellie - Senior Staff Specialist
Dr Melissa Gabriel - Staff Specialist
Prof Peter Shaw - Senior Staff Specialist
Dr Emma McCahon - Staff Specialist
Sheetal Reddy - Clinical Research Associate
Tara Gawthorne - Clinical Research Associate
Lyra Pearson - Clinical Research Associate
Clare Banks - Clinical Research Associate
Kate Deighton - Clinical Research Associate
Anthea Ng - Clinical Research Associate
Adrienne Williams - Clinical Research Associate
Amanda Rush - Clinical Research Associate

Dr Paul Robinson - Respiratory Fellow/PhD
Dr Hiran Selvadurai - Staff Specialist

Students
Melanie Halliday - Master of Science
Michael Ho - USyd MP Honours
Alice Kwok - USyd MP Honours
Feng Liang - USyd MP Honours
Paul Mori - USyd MP Honours

Social Work

Staff
Julie Finlay - Senior Social Worker (PICU)
Susan Khanna - Senior Social Worker (PICU)
Jenny Rose - Student Educator (Sydney West)
Sue Foley - Senior Social Worker, CAPTOS (Psychological Medicine)
Surita Stipp - Social Worker (Diabetes)
Angie de Casanove - Social Worker (Diabetes)

Students
Cadence Barkelew-Catt

Orthopaedic Research and Biotechnology Unit

Staff
A/Prof David Little - Director
Dr Aaron Schindeler - Research Scientist
Dr Michelle McDonald - Research Officer
Dr Kate Sullivan - Research Officer
Dr Renjing Liu - Research Officer
Dr Craig Godfrey - Veterinary Surgeon/PhD
Dr Oliver Birke - Orthopaedic Research Fellow
Alison Morse - Research Assistant
Hoai-Lan Mai - Technical Assistant
Kathy Mikulec - Technical Assistant
Lauren Peacock - Technical Assistant

Students
Nicole Yu - PhD
Jad El-Hoss - PhD
Justin Bobyn - PhD
David Carr - Honours

Respiratory Medicine Research

Staff
Prof Peter van Asperen - Head of Department and MacIntosh Professor
Dr Peter Cooper - Staff Specialist
A/Prof Dominic Fitzgerald - Staff Specialist
Dr Haya Al Subie - Honorary Fellow
Dr Aleisha Neilson - Cystic Fibrosis Fellow
Dr Chetan Pandit - Respiratory Fellow
Brendan Kennedy - Scientific Officer
Samantha Forbes - Research Nurse
Meredith Larkin - Research Nurse
Merilyn McArthur - Research Nurse
Dr Karen McKay - Research Fellow and Coordinator
Tracey Marshall - CNC Asthma Education
Anna Middleton - Research Physiotherapist/PhD
Margherita Pitman - Research Support Worker

Students
Melanie Halliday - Master of Science
Michael Ho - USyd MP Honours
Alice Kwok - USyd MP Honours
Feng Liang - USyd MP Honours
Paul Mori - USyd MP Honours

Sudden Infant Death Syndrome (SIDS) and Sleep Apnoea Research

Staff
A/Prof Karen Waters - Department Head
Dr Rita Machaalani - Post-Doctoral Researcher
Chenda Castro - Clinical Research Coordinator

Students
Dr Joanna MacLean - PhD
Samantha Tang - PhD
Carla Evans - PhD
Rebecca Hensley - Masters
Ihsan Savran - BSc Honours
Courtney Smith - Medicine Honours

The Grace Centre for Newborn Care Research Unit

Staff
Prof Nadia Badawi - Co-Head and Medical Director
A/Prof Kaye Spence - Clinical Nurse Consultant
Dr Peter Barr - Senior Staff Specialist
Kathryn Browning Carmo - Staff Specialist/PhD
Dr Robert Halliday - Staff Specialist and Clinical Manager
Kristen James - Clinical Nurse Specialist
Dr Alison Loughran - Fowlds Staff Specialist/PhD
Dr Amit Trivedi - Staff Specialist
Caroline Karskens - Audit Officer/Research Assistant
Jenny McIntosh - Occupational Therapist
Jan Stewart - Research Nurse

**Students**
Amy Barker - BN Honours
Christine Jorgenson - BN Honours
Sarah McIntyre - PhD
Sharon Laing - PhD
Karen Walker - PhD

**Virology**

**Staff**
A/Prof Alison Kesson - Department Head

**Students**
Hanady Elbab - PhD
Diane Grote - M Med

**Summer Scholarships 2009/10**
Ashley King - Australian Paediatric Surveillance Unit
Alexander Beath - Kids Rehab
Candy Pang - National Centre for Immunisation Research & Surveillance
David Ho - Genetic Metabolic Disorders Research Unit
Hoi Sang Wong - Children’s Cancer Research Unit
Jocelyn Xin Jiang - Centre for Kidney Research
Kyle Buchtmann - Institute for Endocrinology and Diabetes
Leah Gorring - Orthopaedic Research and Biotechnology Unit
Pamela Ajuyah - Institute for Neurosciences and Muscle Research
Saieaswar Krishnan - Institute for Neurosciences and Muscle Research
Vyshnavi Janakan - Kids Rehab
Yuan Rebecca Li - Children’s Cancer Research Unit
Discovering Cures for Kids
## Major Grants awarded in 2009 Calendar Year

<table>
<thead>
<tr>
<th>Funding source</th>
<th>Investigators</th>
<th>Title</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia and New Zealand Intensive Care Society (ANZICS)</td>
<td>Dr M Festa, Mr C Taylor, Dr P Glass, Dr I Sepeit, Prof S Finfer, Prof J Myburgh</td>
<td>SAFE Extrapolation to Paediatric Intensive Care (SAFE EPIC) International Study</td>
<td>$10,000</td>
</tr>
<tr>
<td>Australian and New Zealand Society of Nephrology</td>
<td>Prof J Craig</td>
<td>A multi-component education program for patients with early stage chronic kidney disease</td>
<td>$10,000</td>
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<tr>
<td></td>
<td>Dr A Tong</td>
<td>Treatment adherence after kidney transplantation</td>
<td>$10,000</td>
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<tr>
<td>Australian Cancer Research Fund</td>
<td>Prof P Robinson, Prof R Reddel, A/Prof T Bryan, Prof A Braithwaite, Prof P Tam, Dr M Chircop, Dr M Graham, A/Prof A McCluskey, Prof L Ashman, Dr N Verrills, Dr C Gordon, Dr M Robertson, Prof R Keeford, Dr H Rizos, A/Prof J Byrne, Dr D Catchpoole, Prof R Pearson, Prof M Lavin, Prof B Kemp, Prof B Sarcevic, A/Prof M Kavallaris, Prof R Daly, Prof E Musgrove</td>
<td>The ACRF Chemical Proteomics Centre for Kinomics (CFK)</td>
<td>$3,100,000</td>
</tr>
<tr>
<td>Australian Centre for HIV and Hepatitis Virology Research (ACH2)</td>
<td>Prof A Cunningham, Prof D Jackson, Dr M Kim, Dr W Dyer, A/Prof C Jones</td>
<td>Can HIV Lipopeptide Immunogens induce TH17 Responses</td>
<td>$177,250</td>
</tr>
<tr>
<td>Australian Research Alliance for Children and Youth (ARACY)</td>
<td>Prof E Elliott</td>
<td>A national plan for rare diseases in Australia: building a network of expertise to help families affected by rare diseases.</td>
<td>$16,500</td>
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<tr>
<td>Australian Diabetes Society</td>
<td>Dr M O’Connell, A/Prof F Cameron, A/Prof E Northam, A/Prof G Ambler, A/Prof A Jenkins, A/Prof S Donath</td>
<td>A randomized control trial of continuous subcutaneous insulin infusion (CSII) therapy and its impact upon cognition and behaviour in children and adolescents with type 1 diabetes</td>
<td>$29,000</td>
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<tr>
<td>Australian Orthopaedic Association</td>
<td>A/Prof D Little, Dr O Birke, Dr A Schindeler</td>
<td>Muscle cell contribution to Bone Repair</td>
<td>$38,500</td>
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<tr>
<td>Australian Podiatry Education &amp; Research Foundation</td>
<td>Ms L Begg, A/Prof J Burns, Dr P McLaughlin</td>
<td>Examining the offloading mechanism of the total contact cast for the treatment of diabetic Plantar Foot Ulceration</td>
<td>$8,000</td>
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<tr>
<td>Australian Research Council</td>
<td>Prof P Castaldi, Prof E Elliott, Prof A Scott, Prof S Middleton, Prof J Craig, Dr C D’Este, Dr C Paul, Dr P McElduff, Prof C Pollock, Dr M Haines, Prof S Redman, Prof E Yano, Dr H Watt, Ms K Needham</td>
<td>Organisational change in healthcare: Determinants of effective clinical networks</td>
<td>$292,000</td>
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</tbody>
</table>
## Major Grants awarded in 2009 Calendar Year

<table>
<thead>
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<th>Funding source</th>
<th>Investigators</th>
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</tr>
</thead>
<tbody>
<tr>
<td><strong>Australian Research Council</strong></td>
<td>Prof N Packer, Prof P Robinson, Prof M Itzstein, Prof R Baxter, Prof P Tam, Prof K North, Prof A McCluskey, A/Prof M Molloy, Prof J Götz, Dr M Graham, Dr S Firth, Dr M Baker, Dr G O’Neill, Dr R J Diefenbach, A/Prof T Bryan, Dr R Murray, Dr B Henderson, A/Prof J Byrne, A/Prof A Goodchild, A/Prof P Haynes, Dr M Chircop, Prof M Baker, Prof R Reddel, Prof J Coorssen, Prof A Braithwaite</td>
<td>Beyond Proteomics: Structure and function of protein modifications</td>
<td>$500,000</td>
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<tr>
<td><strong>Australian Rotary Health Research Fund</strong></td>
<td>Dr B Barton, Dr L Dalla-Pozza, Prof P Hazell, Dr M Chow, Prof K Steinbeck, Dr C Hawke</td>
<td>Health-related quality of life and social support in children newly diagnosed with cancer</td>
<td>$36,000</td>
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<tr>
<td><strong>Bone Growth Foundation</strong></td>
<td>Dr M McDonald</td>
<td>Novel Treatment for Augmentation of Distraction Osteogenesis and Bone Healing</td>
<td>$228,648</td>
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<td><strong>Brain Australia Foundation</strong></td>
<td>Prof Brian Owler</td>
<td>Choroidal aquaporin 1 dependent CSF production in the pathogenesis of hydrocephalus</td>
<td>$40,000</td>
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<tr>
<td><strong>Cancer Institute NSW</strong></td>
<td>Dr G McCowage, Prof P Shaw, Dr D Barbaric, Dr D Ziegler, Prof G Marshall, Dr L Dalla Pozza</td>
<td>New mechanisms to facilitate collaborative efforts for paediatric cancer clinical trials</td>
<td>$697,387</td>
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<tr>
<td></td>
<td>Dr W Kaplan, Prof I Dawes, A/Prof C Ormandy, Prof S Clark, A/Prof M Apte, Prof L Khachigian, Dr Phillips, Prof M Molloy, Prof Q Dong, Dr B Cheung, Dr D Catchpoole</td>
<td>Infrastructure support for the ACRF Genomics Bioinformatics Facility</td>
<td>$330,000</td>
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<tr>
<td><strong>Clive and Vera Ramaciotti Foundation</strong></td>
<td>Dr L Dalla-Pozza</td>
<td>Clinical Trials Nurse and Data Manager</td>
<td>$64,000</td>
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<tr>
<td></td>
<td>Prof P Robinson, Prof R Reddel, Dr M Graham, Dr M Chircop, Prof A Braithwaite, A/Prof T Bryan, Dr S Cohen, Dr D Speidel, V Valova, A/Prof B Henderson, Prof J George, A/Prof J Byrne, Dr Peter Hains, Dr N Bache, Dr D Catchpoole, A/Prof D Little</td>
<td>A superior mass spectrometry system for ultra-sensitive cancer phosphoproteomics</td>
<td>$979,371</td>
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<tr>
<td></td>
<td>Dr J Lees</td>
<td>The regulation of Cancer cell migration within solid tissue</td>
<td>$50,000</td>
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<tr>
<td></td>
<td>Prof P Robinson, Prof A McCluskey, Prof R Reddel, Dr M Graham, A/Prof T Bryan, Prof A Braithwaite, Prof P Tam, Dr M Chircop, Prof L Ashman, Dr N Verrills, Dr C Gordon, Dr M Robertson, Prof A Cunningham, Dr R Diefenbach, Dr Andrew Harmon, Prof R Keford, Dr H Rizos, Dr B Henderson, Prof K North, Dr R Murray, Dr G O’Neill, A/Prof J Byrne, Dr D Catchpoole, A/Prof M Kavallaris</td>
<td>To Establish: The Centre for Kinomics (CFK)</td>
<td>$1,000,000</td>
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</tbody>
</table>
## Major Grants awarded in 2009 Calendar Year

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<tr>
<th>Funding source</th>
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<tbody>
<tr>
<td>Commonwealth Department of Health and Ageing</td>
<td>Prof E Elliott, Dr Y Zurynski, Prof P McIntyre, Prof R Booy</td>
<td>Paediatric Active Enhanced Disease Surveillance (PAEDS).</td>
<td>$14,227</td>
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<tr>
<td></td>
<td>Prof J Craig</td>
<td>Funding for Australian based Cochrane Collaboration activities: the Cochrane renal group</td>
<td>$299,160</td>
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<tr>
<td></td>
<td>Prof E Elliott, Dr Y Zurynski</td>
<td>National Surveillance of Rare Childhood Communicable Diseases and Complications Project July 2009 - June 2011 – including Surveillance for the Severe complications of Influenza in children &lt; 15 years for 2010</td>
<td>$335,414</td>
</tr>
<tr>
<td>Foundation for Nemaline Myopathy</td>
<td>Prof K North, Dr N Clarke, Dr B Ilkovski</td>
<td>Dysregulation of calcium homeostasis in nemaline myopathy and related myopathies: exploring a potential new target for therapy</td>
<td>US$43,812</td>
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<td>Foundation for Children</td>
<td>A/Prof K Waters</td>
<td>Ventilatory Control in Paediatric Obstructive sleep Apnoea (OSA)</td>
<td>$66,250</td>
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<tr>
<td>Genzyme</td>
<td>Prof E Elliott, Dr Y Zurynski</td>
<td>Mucopolysaccharidoses in Australia</td>
<td>$35,000</td>
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<tr>
<td>Healthways</td>
<td>Prof N Henley, Prof E Elliott</td>
<td>Alcohol and Pregnancy: Health Promotion messages that work</td>
<td>$76,868</td>
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<tr>
<td>Heart Foundation</td>
<td>Dr S Garnett, Dr S Burrell, Dr H Woodhead, Prof K Steinbeck, A/Prof M Noakes, A/Prof C Cowell, Prof L Baur</td>
<td>Diet intervention for adolescents with prediabetes</td>
<td>$128,209</td>
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<tr>
<td></td>
<td>Prof L Baur, Prof K Steinbeck, Prof A Hill</td>
<td>The Loozit weight management trial in adolescents</td>
<td>$129,000</td>
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<tr>
<td>HeartKids Australia and Manchester Unity</td>
<td>A/Prof D Winlaw</td>
<td>Investigating the Genetic Basis of Congenital Heart Disease</td>
<td>$300,000</td>
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<tr>
<td>Inspire Pharmaceuticals</td>
<td>Dr P Cooper, Prof P van Asperen, A/Prof D Fitzgerald, Dr H Selvadurai, Dr S Towns, Dr K McKay</td>
<td>The TIGER-II Study</td>
<td>$61,310</td>
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<td>Jain Foundation</td>
<td>Dr S Cooper</td>
<td>Identification of Dysferlin domains mediating membrane repair.</td>
<td>$99,400</td>
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<tr>
<td>Kidney Health Australia</td>
<td>Dr G Wong</td>
<td>Monitoring for chronic kidney disease (CKD)</td>
<td>$10,000</td>
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<tr>
<td>Multiple Sclerosis Research Australia</td>
<td>Dr F Brilot-Turville, Dr R Dale</td>
<td>Biomarkers in early paediatric CNS demyelination, and risk of progression to multiple sclerosis</td>
<td>$26,000</td>
</tr>
<tr>
<td>National Heart Foundation of Australia</td>
<td>Prof E Elliott, Dr Y Zurynski</td>
<td>Continued surveillance for Acute Rheumatic Fever in Australia through the Australian Paediatric Surveillance Unit (APSU)</td>
<td>$28,000</td>
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<tr>
<td>Funding source</td>
<td>Investigators</td>
<td>Title</td>
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<tr>
<td>Dr G O’Neill</td>
<td></td>
<td>The Cell biology of glioblastoma infiltration</td>
<td>$508,225</td>
</tr>
<tr>
<td>A/Prof S Alexander, Prof D Harris, Dr Y Wang, Dr YM Wang</td>
<td></td>
<td>Gamma-Delta Tregs, CD8 Tregs and selected natural Tregs to treat renal injury</td>
<td>$583,500</td>
</tr>
<tr>
<td>A/Prof K Donaghue, A/Prof T Jones, Dr N Cheung, Prof J Couper, A/Prof M Craig, A/Prof F Cameron</td>
<td></td>
<td>Intervention to reduce the risk of diabetic retinopathy and early adverse retinal changes in type 1 diabetes</td>
<td>$1,226,875</td>
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<tr>
<td>A/Prof C Cowell, A/Prof D Little, Dr C Munns, Prof B Foster, A/Prof M Zacharin</td>
<td></td>
<td>Bisphosphonate Treatment of Childhood Femoral Head Avascular Necrosis due to Perthes Disease</td>
<td>$1,305,625</td>
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<tr>
<td>Dr S Skinner, Prof M Hickey, Dr E Mattes, A/Prof D Doherty, Prof A Smith, Prof S Rosenthal, Dr S Cooper</td>
<td></td>
<td>Childhood determinants of risky sexual behaviour in adolescence: a prospective cohort study.</td>
<td>$371,025</td>
</tr>
<tr>
<td>Prof R Mattick, Prof S Allsop, Prof J Najman, Dr D Hutchinson, Prof E Elliott, Dr L Burns, Dr S Jacobs</td>
<td></td>
<td>Impact of Parental Alcohol, Tobacco and Other Substance Use on Infant Development and Family Functioning</td>
<td>$1,910,470</td>
</tr>
<tr>
<td>Prof P Sambrook, A/Prof D Little, A/Prof L March, Prof R Buchbinder</td>
<td></td>
<td>A randomised controlled trial to evaluate the effectiveness of zoledronate therapy in osteonecrosis of the hip</td>
<td>$511,425</td>
</tr>
<tr>
<td>Prof I Alexander, Dr M McCormack, A/Prof S Alexander, Prof A Thrasher, Dr S Ginn</td>
<td></td>
<td>Gene therapy, stress haematopoiesis and the risk of malignancy</td>
<td>$595,500</td>
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<tr>
<td>A/Prof R Fulton, Prof R Howman-Giles</td>
<td></td>
<td>The Clinical Impact of Event-based Motion Correction in Paediatric PET/CT Brain Imaging</td>
<td>$267,250</td>
</tr>
<tr>
<td>Prof P Hay, Prof S Touyz, Dr C Meyer, Dr J Arcelus, Dr S Madden, Dr R Crosby, Dr K Pike</td>
<td></td>
<td>Taking a LEAP forward in the treatment of Anorexia Nervosa: A randomised controlled trial</td>
<td>$557,100</td>
</tr>
<tr>
<td>A/Prof A Leach, Prof E Mulholland, Prof M Santosham, A/Prof P Torzillo, A/Prof N Brown, Prof P McIntyre, Ms A Balloch, Dr H Smith-Vaughan, A/Prof S Skull</td>
<td></td>
<td>Single versus combination pneumococcal conjugate vaccines (13PCV and PHID-CV) for high-risk Aboriginal children (COMBO)</td>
<td>$2,870,025</td>
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<tr>
<td>Prof D Reddihough, Dr C Marraffa, Prof P Hazell, Dr K Lee, A/Prof M Kohn, Dr J Wray</td>
<td></td>
<td>Multi-site randomised controlled trial of fluoxetine in children and adolescents with autism.</td>
<td>$481,825</td>
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<tr>
<td>Prof P Barach, A/Prof D Winlaw, Prof R Iedema, A/Prof J Johnson, Dr K Catchpole, A/Prof E Bacha, Dr A Schouten</td>
<td></td>
<td>Human Factors and Patient Safety during Paediatric Heart Surgery: An Evidence-based Approach to Improve Patient Outcome</td>
<td>$780,675</td>
</tr>
<tr>
<td>A/Prof Y D’udekem D’acoz, A/Prof D Winlaw, Dr T Gentles, A/Prof R Weintraub</td>
<td></td>
<td>The Australia and New Zealand Fontan Registry: A Growing Population of Young Adults with Heart Failure</td>
<td>$124,500</td>
</tr>
<tr>
<td>Funding source</td>
<td>Investigators</td>
<td>Title</td>
<td>Amount</td>
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<tr>
<td>---------------</td>
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</tr>
<tr>
<td><strong>National Health and Medical Research Council</strong></td>
<td>Ms L Devereux, Dr D Catchpoole, Dr A Defazio, Dr A Holloway, Dr R Lake, Prof B Robinson, Dr C Schmidt, Ms H Thorne, Dr N Zeps</td>
<td>Australasian Biospecimen Network-Oncology</td>
<td>$2,000,000</td>
</tr>
<tr>
<td></td>
<td>Dr M Haines, Prof J Craig, Prof E Elliot</td>
<td>Determinants of effective clinical networks</td>
<td>$338,850</td>
</tr>
<tr>
<td></td>
<td>A/Prof C Hawley, Ms E Beller, Prof W Hoy, Prof D Johnson, Dr A Cass, Prof J Craig, A/Prof S McDonald, Dr V Perkovic, Prof S Chadban, Prof P Kerr, Dr S Dogra, Dr Z Wang, Dr S McTaggart, Dr D Nicol, A/Prof H Pilmore, Dr K Polkinghorne, Dr G Becker</td>
<td>Australasian Kidney Trials Network</td>
<td>$2,000,000</td>
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<tr>
<td></td>
<td>Prof E Elliott, Prof R Booy, Prof P McIntyre, Dr Y Zurynski, Dr J Buttery, Dr P Richmond, Prof M Gold, Dr H Marshall, Dr J Royle, Dr N Wood</td>
<td>Characterisation of H1N1 Influenza ‘09 in hospitalised children using Paediatric Active Enhanced Diseases Surveillance</td>
<td>$118,513</td>
</tr>
<tr>
<td></td>
<td>Prof R Booy, Prof D Dwyer, Prof E Elliot, Dr L Heron</td>
<td>An unblinded randomized study of influenza A/H1N1 09 resistance to oseltamivir and zanamivir</td>
<td>$149,460</td>
</tr>
<tr>
<td><strong>Neurofibromatosis Association of Australia</strong></td>
<td>Prof K North, Dr G McCowage, Dr S Ardern-Holmes</td>
<td>Optimising evaluation and treatment of the tumour-related complications of Neurofibromatosis 1 and Neurofibromatosis 2: Critical assessment of novel techniques and therapies</td>
<td>$488,572</td>
</tr>
<tr>
<td><strong>NeuroScience Research - Pfizer</strong></td>
<td>Dr R Dale</td>
<td>An autoimmune model of parkinsonism and neuropsychiatric disease: functional effects of auto-antibodies on dopamine metabolism and neurotransmission</td>
<td>$35,000</td>
</tr>
<tr>
<td><strong>NIH</strong></td>
<td>Dr M Shy, Dr G Acsadi, Dr R Finkel, Prof S Scherer, Dr D Herrmann, Dr M Reilly, Dr F Muntoni, A/Prof S Züchner, Dr J Krischer, A/Prof J Burns, Dr D Pareyson</td>
<td>Inherited Neuropathies Consortium</td>
<td>US$6,250,000</td>
</tr>
<tr>
<td><strong>NSW Health</strong></td>
<td>Prof E Elliott, Dr J McAnulty, Prof R Booy</td>
<td>SWINet Surveillance for children hospitalised due to influenza</td>
<td>$15,000</td>
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<tr>
<td><strong>OSMR Science Leveraging Fund</strong></td>
<td>Prof I Alexander</td>
<td>Cellular Therapeutics Infrastructure Enhancement</td>
<td>$657,500</td>
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<tr>
<td><strong>Perpetual Foundation</strong></td>
<td>Dr G O’Neill</td>
<td>Confocal Microscope</td>
<td>$100,000</td>
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<tr>
<td></td>
<td>A/Prof N Badawi</td>
<td>Neurodevelopmental outcome following major cardiac and non-cardiac surgery in infants less than ninety days of age</td>
<td>$17,200</td>
</tr>
</tbody>
</table>
## Major Grants awarded in 2009 Calendar Year

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<tr>
<th>Funding source</th>
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</tr>
</thead>
<tbody>
<tr>
<td><strong>Pfizer Australian Research</strong></td>
<td>Dr K Hale, Prof T Sorrell, Prof P Shaw, Dr Nath</td>
<td>Pharmacokinetics and pharmacodynamics of voriconazole in children with cancer who are receiving this drug as prevention or treatment of suspected or proven invasive fungal infection</td>
<td>$49,913</td>
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<tr>
<td><strong>Pfizer Endocrine Care Paediatric Research</strong></td>
<td>Dr M Zacharin, Dr C Munns, Dr A Kornberg, Prof K North, A/Prof D Little</td>
<td>Clinical trial of Zoledronic acid (Aclasta) in children and adolescents with Duchenne muscular dystrophy</td>
<td>$40,000</td>
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<tr>
<td><strong>Rebecca L. Cooper Medical Research Foundation</strong></td>
<td>Dr F Brilot-Turville, Dr R Dale</td>
<td>Development of test to defect NMDA-R encephalitis in children and prevent long lasting disability</td>
<td>$20,000</td>
</tr>
<tr>
<td></td>
<td>Dr S Garnett, A/Prof C Cowell, Dr M Poon, A/Prof K Donaghue, A/Prof M Craig</td>
<td>To purchase a revco elite PLUS'ULT2586&quot; -80°C Upright Freezer</td>
<td>$18,980</td>
</tr>
<tr>
<td><strong>Roche Products P/L</strong></td>
<td>Prof R Booy</td>
<td>IRIS Influenza Resistance Information Study NV20237</td>
<td>$23,460</td>
</tr>
<tr>
<td></td>
<td>Prof R Booy</td>
<td>An unblinded randomised study of influenza A/H1N1 2009 resistance under standard and double dose oseltamivir treatment</td>
<td>$433,750</td>
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<tr>
<td><strong>SPANZA</strong></td>
<td>Dr A Weatherall</td>
<td>SPANZA research grant for the study: Gabapentin for the management of itch in children with burn injuries - an RCT.</td>
<td>$5,000</td>
</tr>
<tr>
<td><strong>Steve Waugh Foundation</strong></td>
<td>Dr Y Zurynski, Prof E Elliott</td>
<td>Very Rare Diseases in Australia</td>
<td>$15,000</td>
</tr>
<tr>
<td><strong>The Royal Australian Collage of Physiaians</strong></td>
<td>Dr A Durkan</td>
<td>DNA Vaccination against CCL2 and CX3CL1 in a murine model of atherosclerosis</td>
<td>$90,000</td>
</tr>
<tr>
<td><strong>Tourette Syndrome Association</strong></td>
<td>Dr R Dale</td>
<td>Detection and Characterization of pathogenic autoantibodies targeting the dopamine system in PANDAD and Tourette Syndrome.</td>
<td>$71,600</td>
</tr>
<tr>
<td><strong>Vertex Pharmaceuticals Inc</strong></td>
<td>Dr P Cooper, Prof P van Asperen, A/Prof D Fitzgerald, Dr H Selvadurai, Dr S Towns, Dr K McKay</td>
<td>The Strive and Envision Studies</td>
<td>$35,296</td>
</tr>
<tr>
<td><strong>University of Sydney</strong></td>
<td>Dr G Wong</td>
<td>Quality of life of people with chronic kidney disease (QuICK) study</td>
<td>$30,000</td>
</tr>
<tr>
<td></td>
<td>Prof K North, Dr B Barton, A/Prof EA Shores</td>
<td>Early identification of cognitive deficits in children with neurofibromatosisity 1</td>
<td>$50,000</td>
</tr>
<tr>
<td></td>
<td>Prof J Christodoulou, Prof P Tam</td>
<td>Identification of Novel MECP2 Targets: Towards the discovery of Innovative Approaches to the treatment of Rett Syndrome</td>
<td>$50,000</td>
</tr>
</tbody>
</table>
## Major Grants awarded in 2009 Calendar Year

<table>
<thead>
<tr>
<th>Funding source</th>
<th>Investigators</th>
<th>Title</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>University of Sydney</strong></td>
<td>A/Prof K Waters, A/Prof F Lannigan, Prof V Anderson, A/Prof R Horne, A/Prof K Lushington</td>
<td>Does Adenotonsillectomy improve Neurocognition in preschool children with Obstructive Sleep Apnoea</td>
<td>$50,000</td>
</tr>
<tr>
<td><strong>University of Sydney</strong></td>
<td>A/Prof J Byrne</td>
<td>Increased tumor protein D52 expression as a marker of breast cancer predisposition, and a possible role in DNA repair</td>
<td>$40,000</td>
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<tr>
<td><strong>University of Sydney</strong></td>
<td>Dr D Catchpoole, Dr D Skillicorn</td>
<td>Integrated Data-Centered Diagnostics in Paediatric Leukaemia</td>
<td>$20,000</td>
</tr>
<tr>
<td><strong>University of Technology</strong></td>
<td>Prof K North, A/Prof C Jones, Prof J Christodoulou, Dr R Murray, Dr G O’Neill</td>
<td>Correlative light and Electron Microscopy (CLEM) Suite</td>
<td>$150,000</td>
</tr>
<tr>
<td></td>
<td>A/Prof C Clarke, Dr S Turville, Dr R Murray, Dr M Chircop, Dr T Becker, Dr G O’Neill, Dr L Bendell, Dr B Henderson, Prof A Cunningham, Prof P Robinson, Prof P Tam, Prof R Kefford, Prof K North, Dr H Rizos, Dr M Miranda-Saksena</td>
<td>Deltavision Core Image Restoration System with QLM</td>
<td>$100,000</td>
</tr>
<tr>
<td><strong>University of Technology</strong></td>
<td>Dr Paul Kennedy, Dr D Catchpoole</td>
<td>Making Sense of data in childhood cancer with partner organization The Children’s Hospital at Westmead</td>
<td>$30,000</td>
</tr>
<tr>
<td><strong>Wyeth/Pfizer</strong></td>
<td>Prof R Booy</td>
<td>Nasopharyngeal carriage of streptococcus pneumoniae in Tanzanian children with HIV/AIDS and in their primary caregivers</td>
<td>US $91,200</td>
</tr>
</tbody>
</table>

### Fellowsips

<table>
<thead>
<tr>
<th>Funding source</th>
<th>Investigators</th>
<th>Title</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Don and Lorraine Jacquot Fellowship</strong></td>
<td>Dr G Wong</td>
<td>Chronic kidney disease and colorectal cancer – early detection and quality of life</td>
<td>$90,000</td>
</tr>
<tr>
<td><strong>National Health and Medical Research Council</strong></td>
<td>Dr Y Chen</td>
<td>Increased Tumor Protein D52 expression as a marker of tumour predisposition, and a possible role in DNA repair</td>
<td>$285,000</td>
</tr>
</tbody>
</table>

### Scholarships

<table>
<thead>
<tr>
<th>Funding source</th>
<th>Investigators</th>
<th>Title</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cancer Institute NSW</strong></td>
<td>C Bach</td>
<td>Understanding focal adhesion dynamics in cell migration</td>
<td>$50,000</td>
</tr>
<tr>
<td><strong>Fullbright</strong></td>
<td>A/Prof J Burns</td>
<td>Closing in on a cure for Charcot-Marie-Tooth disease</td>
<td>$30,000</td>
</tr>
<tr>
<td><strong>Ministry of Education</strong></td>
<td>N Roslan</td>
<td>Inhibiting tumor protein D52 function for anti-cancer therapy application</td>
<td>$114,824</td>
</tr>
<tr>
<td><strong>The Royal Australian College of Physicians/ Juvenile Diabetes Research Foundation</strong></td>
<td>Dr M Poon</td>
<td>The Changing Phenotype of type 1 Diabetes - The increasing role of the environment</td>
<td>$50,000</td>
</tr>
</tbody>
</table>


Publications

- Dane AP, Cunningham SC, Graf N, Alexander I (2009). Sexually dimorphic patterns of epigenetic DNA genome persistence in the adult mouse uterus and correlation with hepatocellular proliferation. Molecular Therapy 17(9): 1548-54.


Publications


Our research is achieving real and tangible benefits for patients. But we can’t do it without your generosity.

Financial support from the community enables our researchers to tackle some of the most complex problems in paediatric medicine. Our staff have the expertise and the dedication, but funding is vital to provide them with the tools and resources they need to carry out this important work.

Researchers at the Kids Research Institute are deeply grateful for more than $5 million we have received in donations from the community this year. These donations have supported many of the achievements highlighted within this report.

Every gift we receive, no matter how large or small, has the ability to transform the work that we do. Whether it’s aiding a discovery or actually translating what we do in the laboratory into meaningful, new treatments for sick kids, every step we take enabled by your donations is an important step.

One of the most transformational gifts we received this year came through a bequest – a gift left to us in the will of a generous supporter. This donation will support a combination of new and exciting laboratory and patient-based collaborative research projects across Orthopaedics, Bone and Mineral Medicine, Genetics and Renal Medicine. This donation has also bought important research equipment, without which our work could not have moved forward.

Rett Syndrome Research also received a significant boost from community donations during 2009/10. Rett Syndrome is a debilitating neuro-developmental disorder that begins in early infancy and is seen almost exclusively in girls. Children are usually born healthy and show an early period of normal development until the age of six to 18 months of age after which there is a period of developmental regression.

Although there is no cure or specific treatment, our researchers are currently working on ways to improve the lives of these young girls and hopefully one day develop a cure.

Donations received by the Children’s Cancer Research Unit are critical for funding research into the treatment of childhood cancer and to make childhood cancer specimens available for research through the Tumour Bank. This program is working towards a clinical trial for children with high-risk brain tumours who have exhausted conventional treatment options. There are very limited options to fund this type of trial from traditional research grant funding schemes, and we are extremely fortunate to receive $500,000 each year from the Oncology Children’s Foundation, whose funding partnership underpins the program. Without this support, we would not be in a position to embark on Australia’s first gene therapy treatment for children with cancer. This really is a wonderful example of how, working in partnership, we can improve the outcomes for seriously ill children.

The Institute of Neuromuscular Research is undertaking world-leading research into causes and treatments of children with muscle disease. We are grateful to the hard-working supporters who raise a significant proportion of the funds needed by the INMR to continue their research efforts. These donations, combined with the INMR competitive research grants, ensure that we remain at the cutting-edge of paediatric medicine and research.
The Kids Research Institute would like to thank the following donors for their support this year:

Abril Building Solutions  
Alice Styles  
David & Elizabeth Adams  
AMP Foundation  
AOOB  
AOOB Hornsby  
Athanase Yenibis Foundation  
ATR  
Associazione Bagnara Calabra of NSW Sydney Inc  
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Baxter Charitable Foundation  
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C & M Lawyers  
Cafe Ilviszio  
Canberra Rent the Roo  
Charcot-Marie-Tooth Association of Aust  
Children’s Cancer Welfare Services  
CML Finance Solutions Pty Ltd  
Colbridge Pty Ltd  
Combined Civil Group  
Combined Plumbing Services  
Conca D’Oro Classic Lounge  
John Conde AO  
Conveyor & Investments Pty Ltd  
Camel Crane  
Carol Brook  
Daniel Betros  
Patricia Fagan  
FDC Fitout  
FreePour Espresso  
Deepak Gill  
C A Goodwin  
B & T Gorman  
J Graham  
Gresham Partners Ltd  
Geoff Grimish  
Group FX Pty Ltd  
Harvey Norman - Head office  
Heartkids NSW Inc  
Honora Corbett  
Inghams Enterprises Pty Ltd  
Insuitech Pty Ltd  
Jenolan Caves Reserve Trust  
Joseph Boustani  
Kayaking for Kemo Kids  
Killard Excavations Pty Ltd  
Kitchen Complex  
Lady Anne Funerals  
Liangrove Foundation Pty Ltd  
Lions Club NSW-ACT, Public Health Care Foundation  
Lions Club of West Pennant Hills - Cherrybrook Inc.  
Bob & Joanne Liso  
M Projects Pty Ltd  
Macquarie Group Foundation Limited  
Maple-Brown Family Charitable Foundation  
Margaret Saunders  
Toni McCaffery  
Merrett Foundation  
Metleg/Kayrouz  
MGA Motor Repairs  
Samantha Moubarak  
Nalebirch Interiors  
Neurofibromatosis Association of Aust  
Brian & Cassandra Nicholls  
Noel’s Plumbing & Bathroom Supplies P/L  
Novakovic Family  
Omax Coating  
Oncology Children’s Foundation  
Susan O’Sullivan  
Robert Ouvrier  
Owen Miller Foundation  
Pennant Hills High School  
Powerline Concrete Construction  
PSP Alliance  
Radiomarathon  
Rahnch Constructions Pty Ltd  
Rail, Tram & Bus Union  
Ralph First Real Estate  
Rellim Holdings No 2 Pty Ltd  
Rett Syndrome Australian Research Fund  
Ronald Geoffrey Arnott Foundation  
RJ Workspace  
Rotary Club of Bowral-Mittagong  
Rotary Club of Newcastle Harbour  
SAI Global Limited  
SAS Building Maintenance  
Save Our Sons  
Shannon’s Fundraiser  
Shock & Vibration Technologies Pty Ltd  
David Skea  
Rachel Skinner  
Stavros Georgallis  
Snezana Stekovic  
Steve Waugh Foundation  
Sutherland Shire Toy Restoration Centre  
Swift Plumbing  
Switch Australia  
Sydney Cycling Club  
Sydney Tax and Financial Services  
Telestar Communications  
The Diavitiko Association  
Tourism Southern Highlands  
Tri Thai  
Vera Clarke  
VIP Building Projects  
Wingecarribee Shire Council  
Greg Welsh  
Bequests  
Estate Late Bebe Louise Fletcher  
Estate Late Clifton Albert Ellis  
Estate Late George Emmerson Sullivan  
Estate Late Jocelyn Phlug  
Estate Late Karla Slagmolen  
Estate Late Maria Dowhaluk  
Estate Late Valerie Ruth Street  
Estate Late Barbara Kathleen Kendall  
Estate Late Elizabeth Ingrid Cohen  
Estate Late Joan and Peter J Morrissey  
Estate Late Margaret Douglas Brown
Philanthropy is a cornerstone of medical research. On behalf of all our researchers, we thank you sincerely for all your contributions.

Your gift today will play a vital role in enabling us to understand, treat and cure childhood diseases, as well as improving the quality of life for children suffering from serious illness for which there is no cure.

Clinical trials, medical analysis and research cost a staggering amount of money. That is why your support is so important. We need sufficient funding to ensure that our work continues and we continue to deliver the best possible outcomes to sick children across Australia.
How you can help

Every donation counts

To make a donation:

Mail: Fundraising Department
The Children’s Hospital at Westmead
Locked Bag 4001
Westmead NSW 2145

Cheques should be made payable to
The Children’s Hospital at Westmead.

Phone: (02) 9845 3367
Online: www.kidsresearch.org.au