



Telethon Institute for  
Child Health  
Research

ANNUAL REPORT 2011

*Delivering hope through  
life-changing research*



INFECTIOUS DISEASE RESEARCHER  
DR DEBORAH LEHMANN WITH RILEY

PRINCIPAL PARTNER



Telethon Institute for  
Child Health Research

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## *Delivering hope through life-changing research*

How does a research organisation deliver hope?

It is through medical research that one day there will be a cure for children's cancers and asthma.

It is how better treatments are developed for children with cerebral palsy and how it was discovered that a vitamin – folate – could prevent many cases of spina bifida.

We know that when a child is born with or develops a serious disease or disability, their families look to medical research to give them hope for the future.

It's a responsibility we take very seriously.

At the Telethon Institute for Child Health Research, our community not only actively participates in our research projects but informs and shapes what we do through our Consumer and Community Advisory Council and Community Conversations.

This Annual Report is part of our commitment to share more about the research that we are currently doing.

We also have a new, easy to navigate website with an index of every project currently underway – just use the search button and type in your key words.

In this report you will also find research highlights from 2011 where we have delivered on the hope invested in us as we look to find the causes of the most common and devastating conditions and issues affecting children and their families.

Find out more at [www.childhealthresearch.org.au](http://www.childhealthresearch.org.au)



## 2011 HIGHLIGHTS

A major priority of the Institute is to ensure translation of research into action that makes a real difference to the lives of children and families. In 2011, Institute researchers were recognised for their research outputs, their high-level advocacy and their impact on policy.



### PhD's and publications

In 2011, 19 of our students successfully completed their PhD degree and graduated.

Our researchers contributed to 232 publications including journal articles, book chapters, peer-reviewed conference papers and reports.

### Aboriginal health researchers win major Discovery Grants

More than \$1.3 million in competitive funding was awarded to our Centre for Research Excellence in Aboriginal Health and Wellbeing for Indigenous mental health and parenting projects.

The two major grants were part of just 10 awarded nationwide under the Discovery Indigenous scheme from the Australian Research Council.

Both projects are headed by outstanding Indigenous researchers and are focussed on building on the strengths and knowledge within Aboriginal communities to ensure that services are culturally-appropriate, responsive and more effective.

2011 PHD GRADUATES DR MATHEW WELCH  
AND DR HANNAH MOORE

### International search to beat rare childhood brain tumour

An international study led by Australian researchers outlined for the first time the best treatment options for children suffering from meningioma - a rare type of paediatric brain tumour.

Dr Rishi Kotecha's interest in the rare tumour was prompted by two recent cases in Western Australia. With little information about how best to treat the tumours, Dr Kotecha embarked on an international search of the literature and found that aggressive surgical management, rather than radiotherapy, was the best way to treat his patients.

The research, published in *The Lancet Oncology* demonstrated the value of international collaboration in gathering sufficient data for rare diseases.

### Caesarean link to respiratory infections in babies

Babies born by elective caesarean are more likely to be admitted to hospital with the serious respiratory infection, bronchiolitis, in the first year of life.



DR RISHI KOTECHA WITH RORY  
PHOTO COURTESY THE WEST AUSTRALIAN

Dr Hannah Moore analysed linked birth data and hospitalisation records of 212,068 babies over a 10-year period in WA and after adjusting for a range of maternal factors and pregnancy complications, the effect was an 11 per cent increase in hospital admissions.

Published in the international journal *Archives of Disease in Childhood*, this is the first study to link elective caesareans to bronchiolitis.

Dr Moore said this study supports the need for more research into the suspected role of various chemicals (cytokines) that are produced by mothers during labour in priming a newborn's immune system.

## Smoking link to leukaemia

Children whose father smoked more than 15 cigarettes a day around the time of conception may have a 35 per cent higher risk of developing childhood leukaemia.

Dr Elizabeth Milne said the findings fitted with what is already known about how tobacco smoke can damage the DNA in sperm, but these sperm are still able to fertilise an ovum. The study found no increase for those who had previously smoked, suggesting that sperm with normal DNA may be produced after smoking is ceased.

Dr Milne cautioned that the causes of childhood leukaemia are likely to involve many interacting factors of which only one is cigarette smoke. However, it's important that potential fathers know the damage that may be caused to their sperm and have the opportunity to reduce that risk by stopping smoking.



## Telethon Adventurers fund brain tumour fellowship

The Telethon Adventurers announced a new research fellowship to investigate the genes involved in childhood brain tumours.

The Elliot Parish Fellowship in Childhood Cancer Research was awarded to Dr Jacqueline McGlade in December 2011 to fund her research over the next five years.

Dr McGlade will be comparing cancerous and normal tissue to help identify particular genes suspected to be involved in the process of tumour development and survival.



MR STAN PERRON, PROFESSOR FIONA STANLEY AND CLINICAL ASSOC/PROF DEBORAH LEHMANN

## Fiona Stanley Medal winners

In 2011, Mr Stan Perron was presented with the Fiona Stanley Medal for Philanthropy for his loyal and long term support for the Institute. Mr Perron was one of the first people to support our original capital campaign and continues to provide top-up scholarships for our PhD students and has allowed us to bring Dr Jennie Blackwell back to Perth from Cambridge and autism researcher Dr Andrew Whitehouse from Oxford.

Clinical Associate Professor Deborah Lehmann received the Fiona Stanley Medal for Research for her work in infectious diseases in some of the most disadvantaged and isolated communities. With a research focus on pneumonia and otitis media, Dr Lehmann makes regular trips to Papua New Guinea and has led exciting projects in Kalgoorlie and the Goldfields.

## No consistent decrease in child maltreatment

Over the last two decades in developed countries, there has been no consistent decrease in rates of child maltreatment despite a raft of policy initiatives. That was the finding from research published in the prestigious international journal *The Lancet*.

The Institute's Dr Melissa O'Donnell contributed the Australian perspective which was then compared with information from Sweden, England, New Zealand, Manitoba-Canada and the USA.

The research reinforced the need to improve the evidence-base for child protection policies - what are the driving factors, which professionals are seeing these children, and what really works in terms of prevention and early intervention.

## New CP respiratory study

Breathing and airway problems in children and young people with cerebral palsy (CP) can cause serious respiratory problems, sometimes requiring admission to hospital.

In November, we launched the Breathing for Life study, which is being run by the Telethon Institute, The Centre for Cerebral Palsy and Princess Margaret Hospital for Children.

The study will look at the extent and natural history of serious breathing and airway problems in children and young adults with CP so we can work to prevent the progression of these problems before they occur.

[www.breathingforlife.ichr.uwa.edu.au](http://www.breathingforlife.ichr.uwa.edu.au)

## Heath Ledger Scholarships

Five outstanding Institute researchers were awarded the inaugural Heath Ledger Career Development Scholarships in November.

Presented by Heath's father Kim Ledger, the scholarships will enable the researchers to attend conferences and visit research groups nationally and overseas providing an opportunity to meet, learn and share their work with some of the best people in their fields.

The recipients were Dr Alexander Larcombe, Dr Anthony Bosco, Dr Hannah Moore, Dr Monique Robinson and Dr Jenny Downs.

## Books boost child language

Research published in the international journal *First Language* provides more evidence that reading books to young children and helping them visually to follow the story improves a child's language.

Dr Brad Farrant said the findings show that children with more educated mothers have larger vocabularies because they engage in more parent-child book reading. The study also confirmed previous research demonstrating a gender gap favouring girls, who had a significantly greater vocabulary than boys at around 3 years of age.

Parent-child picture book reading provides an excellent opportunity for vocabulary expansion by learning word-object mapping



KIM LEDGER, DR ALEXANDER LARCOMBE AND PROFESSOR FIONA STANLEY

in a more structured setting and involves pointing gestures, joint attention and verbal labelling.

## Results out in Kwinana respiratory health study

The results of a study of 600 children from almost 500 families showed that overall the respiratory health of Kwinana children is about the same as that of children in other areas of Perth.

Dr Peter Franklin said there were very few differences in the parent-reported symptoms.

However, the study did find that children who had lived in Kwinana since before the age of 3 years were more likely to have wheezed at least once in their life when compared to children who had moved to Kwinana after the age of 3 years (42.1 per cent versus 26.4 per cent) but these children did not have increased recent symptoms (wheeze in the previous 12 months).

There was no difference in the results of the breathing tests between Kwinana children and the children from other areas.

## National funding win

More than \$4 million in competitive grants from the National Health and Medical Research Council (NHMRC) was awarded to the Institute in October 2011.

The successful funding applications include:

### Project Grants

- Predicting asthma in young adults, Graham Hall
- Nutrition, obesity and mental health from infancy to adulthood, Wendy Oddy
- Metabolomics, melioidosis and sepsis, Jenefer Blackwell
- Developmental abnormalities in immune mechanisms that protect against respiratory infections and risk for development of asthma, Patrick Holt
- Does abnormal epithelial function facilitate aero-allergen sensitization?, Stephen Stick
- Airway smooth muscle and asthma, Peter Noble
- Testing new drugs using childhood brain tumour models, Nicholas Gottardo

### Australian - European Union Collaborative Research Grants

- Long-term influence of early nutrition on metabolic health, Wendy Oddy

### Career Development Fellowship

- Graham Hall

### Early Career Fellowship

- Hannah Moore

## Fighting meningococcal

Our Vaccine Trials Group has been part of the continued search for a vaccine against Meningococcal B, the last major cause of meningitis for which we don't have a vaccine and the one that most affects West Australians.

Dr Peter Richmond said there is no vaccine available currently to prevent the Meningococcal B strain of the bacteria that accounts for more than 90 per cent of cases in WA.

Adolescents aged between 11 and 17 years were recruited to the trial, which will compare two Meningococcal B vaccines manufactured at two different sites.



DR PETER RICHMOND WITH MEN B STUDY VOLUNTEER RYAN

## Traffic emission linked to low birthweight

Our research has linked traffic emissions to reduced fetal growth.

Assistant Professor Gavin Pereira monitored normal suburb traffic pollution (where air quality guidelines met national standards), and compared it with the birth records of over 1,000 mothers over a period of six years between 2000 and 2006.

The results published in the *Australian and New Zealand Journal of Public Health* show that a baby who would have otherwise attained an optimal birth weight of 3.5kg would be expected to be born 58g lighter. The results reflect about half of the effect observed for maternal smoking during pregnancy among this group.

## Rally for Research

Hundreds of Institute researchers hit the Perth streets on April 14 2011, joining colleagues from other institutes to rally against Australian Government plans to cut medical research funding in the federal budget.

Similar rallies were held around Australia to show the high level of community support for health and medical research.



## Alcohol health warnings protect mums and babies

Our researchers supported calls for mandatory health warning labels on alcohol products as proposed by the Alcohol Education and Rehabilitation Foundation (AERF) following consultation with health experts around Australia, including the Institute.

Professor Carol Bower said it was crucial that women were alerted that consuming alcohol could cause lifelong damage to an unborn child. There is overwhelming evidence that alcohol consumption during pregnancy can cause a spectrum of disorders ranging from birth defects to intellectual disability and behavioural problems.

Some women are still unclear that the national recommendation is to avoid alcohol in pregnancy.

## Children follow in their parent's behaviour footsteps

Parents have an important role to play in teaching their children to understand another person's feelings and point of view.

Brad Farrant investigated the factors that facilitate the development of positive social behaviour in four to six year old children.

Mothers who have higher levels of empathy were more likely to encourage their children to think how others might be feeling, which in turn was associated with greater development of empathy skills in the child. Children with more advanced perspective-taking skills behave more positively with other people.

In other research, Dr Farrant found that young children whose mothers talk with them more frequently, and in more detail about people's thoughts and feelings, tend to be better at taking another's perspective than other children of the same age.

## Most late-talking toddlers turn out ok

Late-talking toddlers are no more likely to experience behavioural and emotional difficulties during childhood and adolescence than children who have normal language development.

Associate Professor Andrew Whitehouse said that while late-talkers have increased levels of behavioural and emotional problems at two years of age, these problems tend not

to continue and they are most likely due to the psychosocial difficulties of not being able to communicate, such as frustration. When the late-talking children 'catch-up' to normal language milestones - which is the case for the majority of children by school-age - the behavioural and emotional problems are no longer apparent.

The study is the first of its kind to track language delay from two years of age through to late adolescence, using data collected from 1387 children from the Raine Study.

The results were published in the prestigious international journal *Pediatrics*.



## Repeated stress in pregnancy linked to children's behaviour

Our research has found a link between the number of stressful events experienced during pregnancy and increased risk of behavioural problems in children.

Dr Monique Robinson said while previous studies have shown a link between stress and poorer outcomes, this study goes further by analysing the timing, amount and kinds of events that lead to poorer outcomes.

Common stressful events include financial and relationship problems, difficult pregnancy, job loss and issues with other children and major life stressors were events such as a death in the family.

The findings, published in the international journal *Development and Psychopathology*, found that two or fewer stresses during pregnancy were not associated with poor child behavioural development, but as the number of stresses increase to three or more, then the risks of more difficult child behaviour increase.

Dr Robinson said the actual type of stress experienced was of less importance than the number of stresses, and there was no specific risk associated with the timing of these stress events - early or late - in the pregnancy.

## World first puts Aussie kids on the map

In a world first, 96 per cent of communities in Australia now have vital information about their children's development, following the mapping of data collected via the Australian Early Development Index (AEDI).

The AEDI results report on 261,147 children (97.5 per cent of the estimated five year old population) from data collected during their first year of school in 2009 to provide a snapshot of children's health and development in different communities.

Professor Steve Zubrick said the AEDI results would allow children everywhere to be developing towards their full potential. Where we see children doing less well than others we need to encourage parents, families and leaders to come together and focus on specific things that can be done to enrich and extend developmental opportunities and expectations for families and children.

[www.aedi.org.au](http://www.aedi.org.au)

## Further evidence of testosterone link to autism

Our research has uncovered more evidence of a link between early testosterone levels and autism.

Dr Andrew Whitehouse used data from the long-running Raine Study to examine the relationship between autism-like behaviours in early childhood among otherwise typically developing girls and the timing of their first period.

The results, published in the *Journal of Autism and Developmental Disorders*, found that girls with autism-like symptoms such as poor eye contact and repetitive behaviours were older at the time of their first period.

Dr Whitehouse says this finding may represent an important piece of the puzzle in understanding the causal influence on autism.

One possible explanation relates to levels of testosterone in the womb. We know that autism affects more boys than girls. This has led to the idea that exposure to enhanced levels of testosterone in-utero may contribute to autism. Prenatal exposure to testosterone is a factor thought to influence the age of a girl's first period.

## Trial begins of first vaccine against Ross River Virus

Each year in Australia, there are more than 5000 cases of Ross River Disease. In WA, most notifications occur in the Kimberley and in a belt in the south west from Mandurah to Capel.

Our Vaccine Trials Group is testing the first vaccine against Ross River Virus, which can cause a combination of arthritis, rash, fever and general fatigue that can come on suddenly. These symptoms usually resolve within 6 months but can last for up to a year.

Dr Peter Richmond said that currently the only way to reduce the risk of contracting Ross River is to take measures to avoid bites from mosquitoes.

## Celebrating 21 years of the Raine study

In 2011, our Raine Study researchers and participants celebrated 21 years of being part of the largest and longest running pregnancy and birth cohort study in the world.

The now young adults have been measured and examined since before birth. As babies, children, teenagers and young adults, they've been assessed on more than 10 separate occasions including having measurements of height, weight, skin folds and blood pressure, fitness testing, asthma and allergy tests, reading, counting, strength and posture. We've collected their teeth, saliva, blood and urine. We have more than 85,000 pieces of information on each one of them. For some, we also have over 2.5 million bits of genetic information.

Thank you Raine kids for contributing to the improvement in healthy outcomes for future generations of children.

## Mums-to-be urged to stress less

Mums-to-be shouldn't worry unnecessarily about potential risks during their pregnancy.

Overestimating risk in pregnancy can lead to higher stress levels in pregnant women which in turn can have a negative impact on the unborn



RAINE STUDY PARTICIPANTS CELEBRATE AT A PARTY HELD AT GOVERNMENT HOUSE

child's future physical and mental health.

Dr Monique Robinson said there are a number of factors that may influence the development of an over-estimation of risk. One is the historical context - until around 1935 and the introduction of penicillin and safer C-sections, the risk of death for mother and child during pregnancy and birth was very high. The Thalidomide disaster of the early 1960s and the suffering that it caused also diminished the public trust in the safety of medication during pregnancy.

Dr Robinson said higher stress during pregnancy can also lead to increased stress for the mother postnatally.

## Vitamin D deficiency affects lung growth and function

Our research has discovered the first concrete evidence linking Vitamin D deficiency with poorer lung function and changes in lung growth.

Dr Graeme Zosky said this has important implications for the potential prevention of lung diseases such as asthma and chronic obstructive pulmonary disease (COPD).

The results of this study clearly demonstrate that Vitamin D deficiency alters lung growth resulting in lower lung volume and decreased lung function. More research is needed to see if there is a benefit in giving Vitamin D supplements to pregnant women or babies at higher risk of lung disease as a preventative strategy.

The findings were published in the American Thoracic Society's *American Journal of Respiratory and Critical Care Medicine*.

## Pneumonia rates improve in Aboriginal children

The pneumococcal vaccine program has contributed to closing of the gap in serious infections in Aboriginal children, with our research showing that hospitalisations for pneumonia across Western Australia have declined in Aboriginal children while rates for non-Aboriginal children have remained the same.

Dr Hannah Moore said the disparity between Aboriginal and non-Aboriginal children has declined by a third. The gap in hospitalisations for Aboriginal kids was 15 times higher in the mid-1990's, whereas in the mid-2000's it was around 10 times higher. While there has been a decline in the gap between Aboriginal and non-Aboriginal kids, pneumonia still affects far too many Aboriginal children.

The unique Australian pneumococcal vaccine program is likely to have had a contributing effect on the decline but changes in socioeconomic factors such as education, income, treatment of water supplies and household crowding have also had an impact.



## CHAIRMAN'S REPORT

The past year has been a period of significant change for the Telethon Institute – one that both signifies the end of an era, but also positions the Institute very positively for an exciting future.

In May 2011, the Institute's Founding Director, Professor Fiona Stanley, indicated to the Board her intention to retire from the position at the end of the year.

While the decision was not unexpected, the reality of finding a replacement for such a visionary and inspirational leader was undoubtedly going to be a challenge.

We were also conscious of the desire of both the Institute and the broader community to honour and celebrate Fiona's exceptional contribution to research and advocacy for children and families.

An international search to recruit an outstanding leader in child health research was begun immediately, led with thoroughness and vigour by Mr Michael McAnearney from Gerard Daniels. He literally scoured the globe to interview potential candidates from Europe, North America and Australia.

Out of a high calibre field, the successful candidate was Professor Jonathan Carapetis, who currently heads the Menzies School of Health Research in Darwin.

Not only does Jonathan have impeccable research and clinical credentials, his leadership experience, passion and vision for child health research gives us great confidence that he is the right person to take the Institute into its exciting next phase.

Jonathan will take up the position in July 2012.

Professor Stanley has graciously agreed to take on the role of the Institute's Patron, while continuing as a Chief Investigator on a number of active grants and as a mentor to up and coming researchers.

In terms of major change, there has also been significant progress on the design of the Institute's \$100 million facility within the State's New Children's Hospital at the QEII Medical Centre campus.

The Board is grateful to the State and Commonwealth Governments for their very generous provision of funding to build and fit out the facility. This support means the Institute can look forward to moving into a bigger, state-of-the-art, collaborative research environment in 2016, without having to divert funds from its research activities.

A high priority for the Board continues to be the need to address the growing gap between grant funding and the actual costs of research. We will continue to make representations to the State and Federal Governments on this infrastructure funding issue as well as expanding our effort to secure greater philanthropic support.

My personal thanks go to my fellow Board members for their time and commitment in what has been an exciting and challenging year. I particularly recognise the contribution of Professor Rhonda Marriott who is resigning as a Director as she takes up a research position at the Institute. Rhonda also headed the Institute's Aboriginal Collaborative Council Advising on Research and Evaluation (ACCARE).

I would also like to recognise Professor Moira Clay who has taken on the role of Acting Director in the interim period. Moira has maintained the momentum of the Institute as well as implementing a new faculty structure and other initiatives.

It is, however, a tribute to Fiona Stanley that the Institute has continued to function so effectively after her retirement. Fiona has said she chose her time to leave when she was confident that the Institute had the right people to carry forward the Institute's vision, funding arrangements for the new building secured and the credentials to recruit an outstanding new Director.

There has been an extraordinary outpouring of appreciation and respect at the various functions that have acknowledged Fiona's career and contribution. From the staff farewells to the Festschrift that attracted a host of national and international luminaries, the common themes have been her sharp intellect, passion for evidence, her generosity of spirit and her commitment to social justice.

They are values that are now firmly embedded in the culture of the Institute and will reflect her legacy for years to come.

**John Langoulant AO**  
Chairman



## BOARD OF DIRECTORS

The Board of Directors governs the overall business of the Institute and meets six times annually. Board members serve on a voluntary basis. In order to carry out business effectively, various committees support the Board by offering advice in specific areas.



**JOHN LANGOULANT AO**

Chair, Telethon Institute for Child Health Research; Chief Executive, Oakajee Port and Rail; Chair, Government Employees' Superannuation Board; Chair, Leadership WA; Deputy Chair, Western Australian Ballet; Member, Senate of The University of Western Australia; Board Member, Council of Australian Governments' Reform Council; Board Member, Chamber of Commerce and Industry WA; Board Member, Committee for Perth; Chair, Dampier to Bunbury Pipeline.



**MOIRA CLAY**

Acting Director (from 1 Jan 2012) and Director of Academic & Research Services, Telethon Institute for Child Health Research; President-Elect, Australasian Research Management Society; Chair, Centre for Physical Activity and Nutrition Research Advisory Committee; Former President of the Australian Society for Medical Research; Chair, Health and Medical Research Review Working Group, Association of Australian Medical Research Institutes.



**JEFF DOWLING**

Former Managing Partner, Ernst & Young Western Region; Fellow, Australian Institute of Company Directors; Fellow, Institute of Chartered Accountants Australia; Fellow, Financial Services Institute of Australasia; Board Member, West Australian Symphony Orchestra; Former Member of Board of Trustees, United Way; Director, Atlas Iron Limited; Director, Neptune Marine Services Limited.



**ANNE KELSO AO**

Director, World Health Organization Collaborating Centre for Reference and Research on Influenza; Honorary Professorial Fellow, The University of Melbourne; Honorary Senior Principal Research Fellow, Queensland Institute of Medical Research; Member, Council of Queensland University of Technology; Member of Board of Trustees, International Society for Influenza and other Respiratory Virus Diseases; Board Member, Florey Neuroscience Institutes.



**MICHAEL MANFORD**

Executive Chairman, Patersons Securities Limited; Chairman, Patersons Asset Management; Board Member, St Hilda's Anglican School for Girls; Panel Member, ASIC Markets Disciplinary Panel.



**RHONDA MARRIOTT**

Director, Kulbardi Aboriginal Centre, Murdoch University; Chair (to 31 Dec 2011), Aboriginal Collaborative Council Advising on Research and Evaluation; Board Member, Public Health Advocacy Institute of Western Australia.



**JIM MCGINTY**

Chairman, Health Workforce Australia; Board Member, Australian General Practice Network; Former WA State Health Minister; Former WA Attorney General.



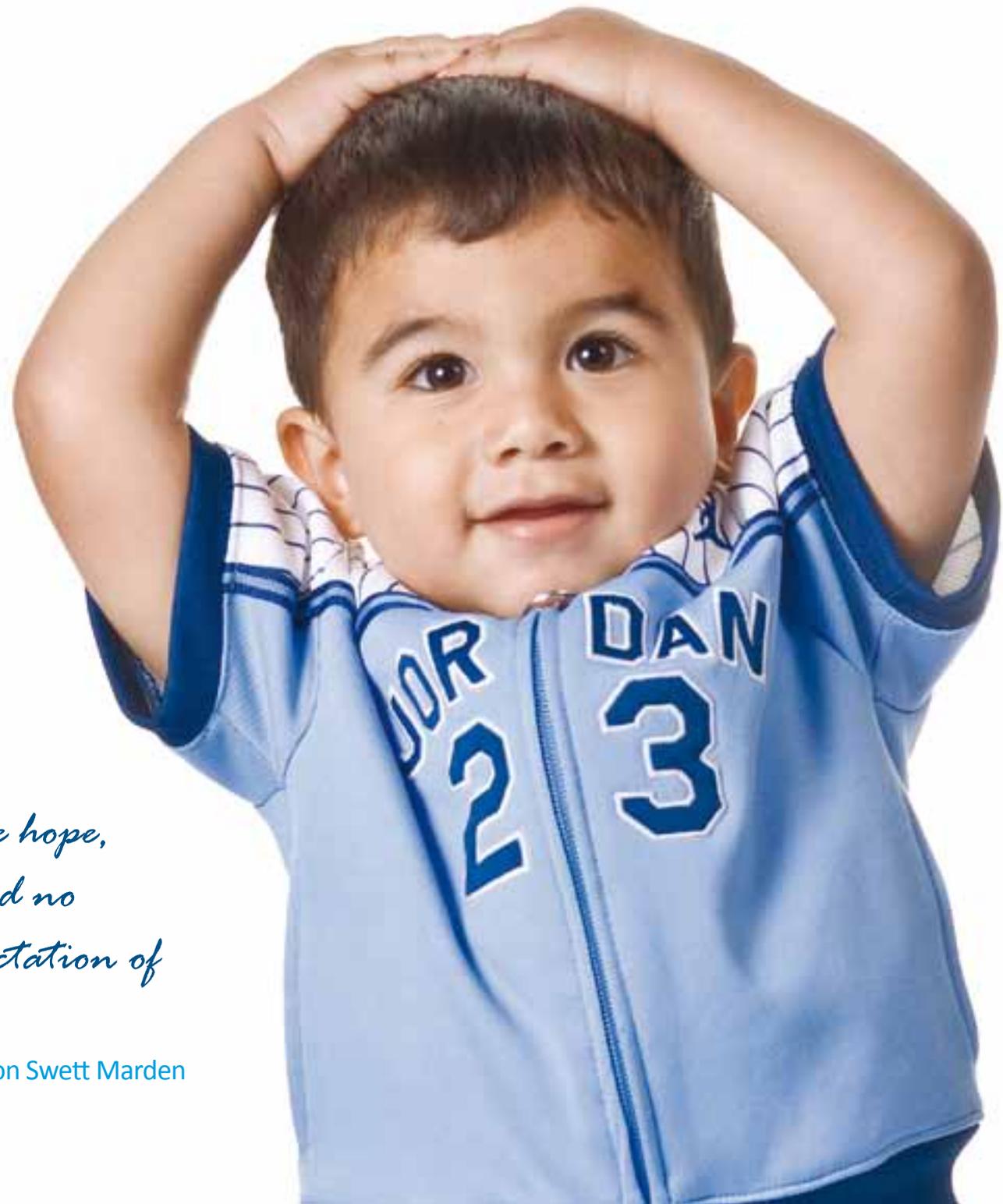
**MARGARET SEARES AO**

Former Senior Deputy Vice-Chancellor, The University of Western Australia; Board Member, Synergy; Board Member, Perth International Arts Festival; Board Member, The Creative Industries Innovation Centre; Board Member, Chamber of Arts and Commerce; Board Member, Education Investment Fund; Board Member, National Research Infrastructure Council; Fellow, Australian Institute of Company Directors.



**FIONA STANLEY AC**

Director (to 31 Dec 2011) and Patron (from 1 Jan 2012), Telethon Institute for Child Health Research; Distinguished Research Professor, School of Paediatrics and Child Health, The University of Western Australia; Professorial Fellow, The University of Melbourne; Prime Minister's Science, Engineering and Innovation Council; Australian of the Year 2003.



*There is no medicine like hope,  
no incentive so great, and no  
tonic so powerful as expectation of  
something tomorrow.*

- Orison Swett Marden

## ACTING DIRECTOR'S REPORT

It has been a great honour, albeit a busy one, to take on the role of Acting Director of the Telethon Institute.

The priority has been to maintain momentum in the period leading up to the arrival of our incoming Director, Professor Jonathan Carapetis, in July 2012.

The Board has been clear that they did not see this period as one of a holding pattern, but one where the Institute would continue to vigorously pursue its research objectives and its advocacy.

Our focus over the past year has been fostering and supporting the next generation of research leaders, who will be so critical as we strive to address current and future health challenges for our children. One of the major initiatives has been implementation of a new Faculty-based research career path, which recognises the diversity of research activities conducted at the Institute through a series of appointment levels.

The Faculty is our senior research leadership group including senior scientists from across all discipline areas of the Institute. The Faculty provides strategic advice to the Director on matters relating to research initiatives that promote and foster the conduct of high quality research across the Institute, the application of research, recruitment and retention of high quality researchers and the training of the next generation of research leaders. Researchers are appointed to Faculty by an external committee on criteria of sustained research performance.

Our young researchers face considerable challenges in developing their careers in today's

national and global research environment. With this in mind, we have developed a number of programs to support our early to mid career researchers who have demonstrated potential for future leadership.

I would particularly like to highlight our new Research Leadership Program that we have developed in collaboration with Organisational and Staff Development Services at the University of Western Australia. This innovative program will be conducted annually for 10 of our early to mid career researchers who have demonstrated outstanding leadership potential. The program involves a series of leadership workshops, in addition the Leadership Team have met with a number of outstanding community and political leaders to hear about their leadership journey and get their reflections on some of the important characteristics of leadership. We are thrilled with how participants in the program are progressing and stepping up to meet the challenges of leadership.

Our major advocacy activity has been related to presenting both the sector and the Institute's submission to the Strategic Review of Health and Medical Research in Australia (the McKeon review).

I was very pleased to Chair the panel for the AAMRI (Association of Australian Medical Research Institutes) submission which presented a bold vision for a sustainable health and medical research sector to address the health needs of our nation and the rapidly rising costs of health care.

The Institute has provided a range of relevant case studies to the McKeon Review Committee. We also advocated for the need to harmonise the definitions surrounding, and whole of system understanding of, the meaning of translational, applied and implementation research. Flowing on from this is a requirement for new pathways into career support for researchers in non-traditional areas.

Overall, the Institute has had success in nationally competitive grants in the past year in line with the national average, but is actively working to lift that success rate.

There is a general concern that the share of national medical research grants to Western Australia have been falling in recent years and the Institute supports representations to the NHMRC for ways to redress this imbalance.

I am very pleased that 19 of our students successfully completed their PhD degrees and graduated in 2011. There has also been a significant increase in the number of peer reviewed journal articles, book chapters, conference papers and reports with 232 high impact publications over the year.

These outputs particularly reflect the Institute's commitment to research excellence, translation of that work into policy and practice and positions the Institute very positively for the arrival of our new Director.

**Professor Moira Clay**  
**Acting Director**



# FAREWELL FIONA

We knew it would happen one day, but there was still surprise and sadness when our Founding Director, Professor Fiona Stanley AC, announced her intention to retire as Director at the end of 2011 after 21 years at the helm.

While Fiona has an ongoing program of research at the Institute and has agreed to take on the role of Patron, we wanted to honour and thank an inspirational leader whose intellect, passion and generosity had created such a special place to work and study.

The events held included Staff Farewell Morning Tea, The F Party – Fiona’s Final Festive Farewell, The Fiona Stanley Festschrift – Symposium and Celebratory Dinner and The Fiona Stanley Tribute Fund – Keeping the Dream Alive.



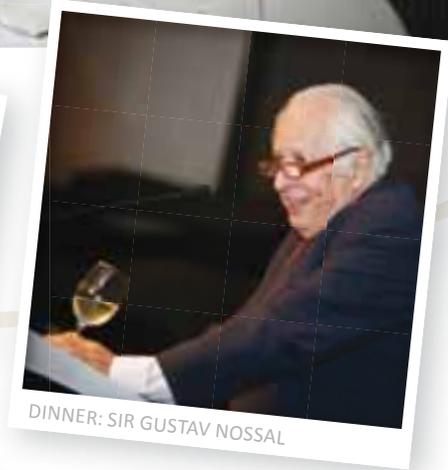
TRIBUTE LUNCH: THOMAS MAHER (APACHE), RICHARD GOYDER (WESFARMERS), JACK BENDAT, FIONA STANLEY AND KERRY STOKES (SEVEN WEST MEDIA)



DINNER: FIONA STANLEY, STEVE TASSEF & TAYLA TASSEF



TRIBUTE LUNCH: FIONA STANLEY



DINNER: SIR GUSTAV NOSSAL



DINNER: JONATHAN CARAPETIS, MARK CALLEJA, MOIRA CLAY & JOHN LANGOULANT



F-PARTY: FIONA GETS INTO THE SPIRIT WITH A DAME EDNA IMPERSONATION



SYMPOSIUM: CANADIAN RESEARCHER CLYDE HERTZMAN



DINNER: CLIFTON BIENDURRY FROM NOMAD TWO WORLDS



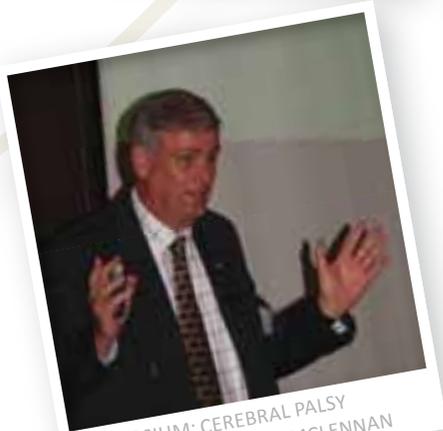
DINNER: ANN SANSON, LANCE EMERSON & PETER WILLS



TRIBUTE LUNCH: BASIL ZEMPLAS WITH JACK BENDAT



DINNER: KEVIN CAMPBELL, DEBORAH LEHMANN, HARVEY COATES & LYN COATES



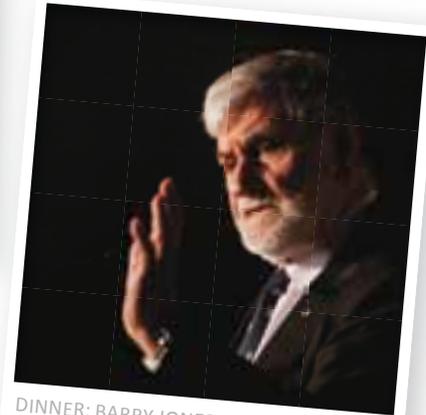
SYMPOSIUM: CEREBRAL PALSY RESEARCHER ALASTAIR MCLENNAN



F-PARTY: INSTITUTE STAFF FAREWELL FIONA IN STYLE



SYMPOSIUM: ABORIGINAL RESEARCHER SANDRA EADES



DINNER: BARRY JONES



DINNER: KIM HAMES, ALYSSA LOFFLER & BEN LOFFLER



DINNER: FIONA STANLEY AND JONATHAN CARAPETIS



SYMPOSIUM: RAINE STUDY PARTICIPANT JESSICA APPELYARD



F-PARTY: DRESSING UP AS FIONA



TRIBUTE LUNCH: FIONA STANLEY WITH PAUL KELLY

## OUR SUPPORTERS



Thanks to all our supporters for their wonderful generosity which contributes so much to our aim of improving the health and wellbeing of children. Our donors not only give practical support but inspire the Telethon Institute's researchers and support staff to strive to achieve excellence in all they do – thank you to each and every individual and company who make such a difference.

### THANKS TELETHON

As the Institute's Principal Partner, Channel 7 Telethon is the largest single donor to child health research in the State. Since the very beginning of Telethon, the Institute has been a major beneficiary and its vital research would not be possible without the commitment and dedication of the Telethon team and the many thousands of Western Australians who donate to Telethon.

Thanks Telethon and thanks Western Australia for your ongoing support.



KERRY STOKES AC,  
CHAIRMAN OF  
CHANNEL 7, WITH  
ADVENTURERS  
CO-FOUNDERS  
RICK PARISH AND  
PETER WILSON  
AND FIONA  
STANLEY.



## Telethon Adventurers Raise \$1.5 million

The Telethon Adventurers launched their new partnership with Channel 7 Telethon early in 2011 and went on to raise \$1.5 million for brain tumour research at the Institute.

Throughout the year hundreds of Adventurers from every walk of life crossed Australia and the globe, climbed mountains and jumped from airplanes to wage their war against cancer.

For some of the Adventurers, like the co-founder Rick Parish, the war on cancer is very personal as they have lost a child to brain cancer or have a child battling with the disease.

Woolworths joined the Telethon Adventurers, holding a bike ride from Esperance to Perth and a fundraising promotion in all WA stores.



VICTORIA O'NEILL  
RAISED FUNDS FOR THE  
TELETHON ADVENTURERS  
BY JUMPING OUT OF  
A PLANE AND WAS  
RECOGNISED FOR  
HER ACHIEVEMENT  
WITH THE "TELETHON  
ADVENTURER OF THE  
YEAR" AWARD.



## Children's Leukaemia and Cancer Research Foundation underpins Institute's cancer research

In 2011, the Children's Leukaemia and Cancer Research Foundation celebrated its 30th anniversary.

Since the establishment of the Telethon Institute, the Foundation has provided significant and critical funding to the Institute's cancer laboratory.



In 1984, the Foundation funded the cancer research laboratory based at PMH and two researchers. Today, they fund seven Telethon Institute researchers and have assisted the overall growth of the cancer research team which has more than 20 members. Thanks to the Foundation and their supporters including their major supporter, Woolworths.



GEOFF CATTACH, CHAIRMAN OF THE CHILDREN'S LEUKAEMIA AND CANCER RESEARCH FOUNDATION PRESENTING THE FOUNDATION'S FELLOWSHIP TO LEUKAEMIA RESEARCHER, DR ALEX BEESLEY.

COMMISSIONER O'CALLAGHAN EXPLORES THE BRIGHT BLUE 3D IMAGING MACHINE WITH INSTITUTE BRAIN TUMOUR RESEARCHERS RAELENE ENDERSBY AND DR NICK GOTTARDO.



## Bright Blue ride for research

In September 2011, the Police Commissioner, Karl O'Callaghan led a large group of volunteer police motorcyclists on the week long Wall to Wall Ride to Canberra. They raised \$250,000 contributing to the purchase of the only 3D Molecular Imaging Machine in the Southern Hemisphere to aid cancer research.

The machine tests laboratory-grown tumours, enabling researchers to determine the best possible treatment for patients. Thanks to Bright Blue, the Police Commissioner and the hundreds of Western Australian police officers and their families and supporters who contribute so much to our cancer research.





## Pioneering pneumococcal research

When six month old Allegra Scafidas died from pneumococcal meningitis in 2010, her parents Elias Scafidas and Nhon Vo wanted to do something to ensure that no other child misses out on life-saving vaccines. In 2011, they established the Allegra Scafidas Fund in partnership with the Telethon Institute with a gift of \$250,000. Their aim is to build the fund to establish a pneumococcal laboratory to target more than 90 strains of the bacterial family that killed their daughter.

RESEARCH ASSISTANT, KARLI CORSCADDEN WITH DR PETER RICHMOND, HEAD OF THE INSTITUTE'S VACCINE TRIALS RESEARCH GROUP IN THE NEWLY ESTABLISHED ALLEGRA SCAFIDAS LABORATORY



TELETHON  
CHAIRMAN  
RICHARD COURT AC  
CONGRATULATES  
STAN PERRON, THE  
2011 RECIPIENT  
OF THE FIONA  
STANLEY  
MEDAL FOR  
PHILANTHROPY.

## Stan Perron Charitable Foundation

Through the Stan Perron Charitable Foundation, Stan has been supporting the Institute since its establishment. He contributed to the capital campaign which resulted in the construction of the Institute's building in Subiaco and has continued to provide scholarships and fellowships for researchers.



## Mitchy's Legacy

In 2011, the family of Michele "Mitchy" Anderson gave her estate to the Telethon Institute to establish the Michele Anderson Fund for disability research.

Michele, who died in 2011 at the age of 55, had a form of Down syndrome and though she had a limited vocabulary she was a great communicator and had an excellent memory and was much loved by her family and friends.



## Thanks acQuire

For the past eight years, the Telethon Institute has been the primary community charity partner of acQuire Technology Solutions.

The Australian-based global and employee-owned company provides Geoscientific Information Management solutions to the natural resources industry.

CEO Warren Cook, said the partnership with the Telethon Institute is extremely rewarding and that connecting with our community, specifically with organisations like the Institute, is an integral aspect of acQuire's culture.



## Thank you to all our donors

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THE BROOKFIELD MULTIPLEX TEAM  
PRESENTED THE \$100,000 CHEQUE TO  
PROFESSOR FIONA STANLEY IN MAY.

## Thanks Brookfield Multiplex

The 'BMX Bandits' of Brookfield Multiplex, contractor for the Fiona Stanley Hospital, raised more than \$100,000 in their fundraising efforts for the Telethon Institute.

Competing in the 2011 Busselton Ironman 70.3, held in early May, they harnessed their competitive spirit to double their initial target of \$50,000.

Thanks so much to the Brookfield Multiplex team and the many contractors working on the hospital construction that supported the team. It's because of dedicated and motivated supporters like Brookfield Multiplex that much of our work at the Telethon Institute is able to continue.



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In the following pages we provide a snapshot of the projects and studies undertaken in the key research areas of the Institute. This is just a taste of the more than 200 studies currently underway. Full reports for all projects can be found on our website and in our scientific annual report, available at

[www.childhealthresearch.org.au](http://www.childhealthresearch.org.au)



## Research overview - ABORIGINAL HEALTH

### *Flagship project to improve Aboriginal health*

Even before they're born, Aboriginal children face far greater hurdles than most other Australian children.

The Telethon Institute works in partnership with Aboriginal researchers and communities to better understand and address the complex factors affecting the health and wellbeing of Aboriginal children.

In October 2010, funding was awarded under the National Health and Medical Research Council Centre for Research Excellence Scheme to establish a national collaboration in Aboriginal health and wellbeing.

As a result, the Centre for Research Excellence in Aboriginal Health and Wellbeing (CREAHW) was established with a \$2.5 million grant over five years.

The CREAHW is a strategic program of intervention research that is focused on achieving radical and sustainable change for the Aboriginal community and improving the lives of Aboriginal people.

One of the 10 chief investigators, Professor Fiona Stanley, said the innovative research program would generate vital information to help close the gap.

"The key issue to be addressed in this program is why the majority of health and social services have failed to bring about any significant improvements in the health and wellbeing of Aboriginal people," Professor Stanley said.

"It's time to get to the core of why these programs aren't working and find out what it

is about those that do deliver that makes them effective."

The program is a unique validation of Aboriginal knowledge and demonstration of Indigenous methodology involving a multi-disciplinary team of Aboriginal and non-Aboriginal researchers, who will contribute to the body of knowledge, work transparently with the Aboriginal community and embrace Aboriginal culture and ways of thinking.

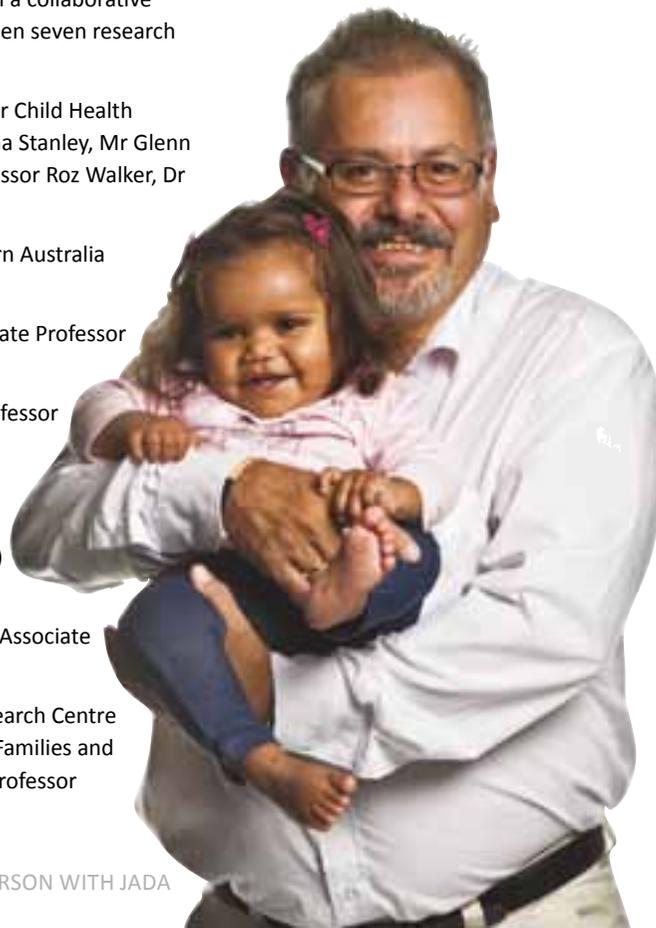
The Chief Investigators form a collaborative research partnership between seven research institutions:

- The Telethon Institute for Child Health Research (Professor Fiona Stanley, Mr Glenn Pearson, Associate Professor Roz Walker, Dr Michael Wright)
- The University of Western Australia (Professor Pat Dudgeon)
- Curtin University (Associate Professor Dawn Bessarab)
- Murdoch University (Professor Rhonda Marriott)
- The Baker IDI Heart and Diabetes Institute (Professor Sandra Eades)
- Combined Universities Centre for Rural Health (Associate Professor Juli Coffin)
- Pindi Pindi National Research Centre for Aboriginal Children, Families and Community (Associate Professor Cheryl Kickett-Tucker)

Fellow chief investigator Glenn Pearson said the research will look at cultural and other factors, such as racism, in how services are delivered and received by Aboriginal people.

"We won't just be comparing Aboriginal and non-Aboriginal outcomes, we'll focus on the disparity between Aboriginal communities in the hope that we can identify why some programs and services are more effective than others," Mr Pearson said.

A priority for CREAHW is to provide advice to government agencies and policy makers via research and policy briefs with the first brief presented in 2011. CREAHW has also published over 20 peer-reviewed journal articles and book chapters and has disseminated research outcomes via a new website, retreats, seminars, newsletters and annual report.



RESEARCHER GLENN PEARSON WITH JADA

For more information about our research in the area of ABORIGINAL HEALTH, visit [www.childhealthresearch.org.au](http://www.childhealthresearch.org.au)

Other projects in this area include:

- Western Australian Aboriginal Child Health Survey
- Working Together: Indigenous Mental Health Textbook
- Newborn Asthma and Parental Smoking Project
- Staying on Track: Reducing Substance Misuse for Aboriginal Young People in Port Hedland and Newman
- Implementation and evaluation of the Australia Early Development Index (Indigenous adaptation) in the Western Desert communities
- Evaluating the Halls Creek Community Families Program
- Addressing Aboriginal rates of organ donation in WA

## Research overview - ASTHMA, ALLERGY AND RESPIRATORY DISEASE

### *Preventing lung disease in babies with cystic fibrosis*

Cystic fibrosis (CF) is a devastating condition that leads to premature lung damage and impacts severely on a child's quality of life. Dedicated to investigating the cause of CF and developing new treatments, the studies led by Professor Stephen Stick's CF research team at the Institute are diverse and ground-breaking.

Working as part of the Australian Respiratory Early Surveillance Team for Cystic Fibrosis (AREST CF), Institute researchers have been

building on previous studies pioneering the use of CT scans to detect early lung damage in the very young. Findings indicated that infants and young children with CF showed evidence of infection and reduced lung function from an early age highlighting the need for new treatments to progress or even reverse the damage in the very young.

Progressing that research, the COMBAT CF program was launched in August 2011 with a grant of \$3.8 million awarded by the USA Cystic Fibrosis Foundation to the Institute to coordinate the research across 10 sites in Australia and New Zealand.

The research will be the first clinical interventional trial looking at the use of the approved antibiotic azithromycin in the prevention of lung disease in infants. Currently used as a treatment for CF, this study of 130 infants will look at the drug's potential as a preventative measure against lung disease in the very young. Recruitment has begun, with the trial beginning mid-2012.

Under the leadership of Professor Stick, the Institute was awarded a National Health and Medical Research Council (NHMRC) Centre of Research Excellence grant in 2011 to study chronic lung disorders that start in early life, with a primary focus on cystic fibrosis.

Our Paediatric Respiratory Physiology team headed by Professor Graham Hall won a NHMRC grant in October 2011 for important research into the long term outcomes of infant lung function in cystic fibrosis. The funding of just over \$484,000 will allow further

implementation of a unique Institute-designed program for the measurement of lung function in babies.

The Institute's CF team was also successful in making the shortlist for a major collaborative research project being funded by Cystic Fibrosis Australia and Cystic Fibrosis Western Australia. Successful applicants for the five year project aimed at eliminating or neutralising cystic fibrosis will be announced in the first half of 2012.

For more information about our research in the area of ASTHMA, ALLERGY AND RESPIRATORY DISEASE, visit [www.childhealthresearch.org.au](http://www.childhealthresearch.org.au)

Other projects in this area include:

- Impact of air pollution during pregnancy on infant lung function
- The influence of preterm birth on lung structure and function in school-age children
- Characterising the respiratory health of young children born preterm
- Lung function in young children with recurrent wheeze
- House dust mite allergy
- The role of the airway epithelium in children with asthma
- Relationships between Vitamin D status and asthma and allergy development in the WA Pregnancy Cohort (Raine) study
- Assessing risk for asthma development amongst infants



CYSTIC FIBROSIS RESEARCHER  
GRAHAM HALL WITH KAITLYN

# Research overview - BIOINFORMATICS, BIostatISTICS AND DATA SERVICES

## *Innovative bioinformatics for innovative research*

The collection, management and analysis of data underpins the very foundations of scientific research work. Our researchers continually generate millions of results that need to be stored, protected and combined with large amounts of information from public databases to better enhance our understanding of human disease and our ability to tackle it.

Bioinformatics is a cutting edge research field that uses computer technology, mathematics and statistics to help us achieve this. The Institute has a dedicated bioinformatics and data services team that plays a vital role in providing the technology, skills and system support to collect and manage vast arrays of data and to improve the understanding of complex biological processes and human diseases.

2011 saw the development and expansion of a number of bioinformatics projects focusing on developing computer technologies to enhance the access to, and use of, research databases.

Significant progress was made with the development of a flexible and secure software package that allows the pooling and analysis of remotely located research databases. This software allows multi-site collaborations to bring their data together without having to transfer all data to a central repository, which is the more traditional method that can run into hurdles with privacy and legal requirements. The bioinformatics team developed and rolled out their software as part of their role in the International Collaboration for Autism Registry Epidemiology (iCARE) project, which is aimed

at determining autism risk factors and trends using datasets from six different countries.

This software was presented at a major international autism conference in the US in May 2011 and received positive feedback from delegates. Strong support has also been received from Autism Speaks (USA), which has offered additional funding for the Institute team to further develop the IT hub of the iCARE project in 2012. The team is in the process of producing a public version of the software to be released to researchers during 2012, and is a central part of the iCARE team's application for funding from the National Institute for Health for the next five years.

Creating software programs to help determine the mechanisms that cause childhood brain tumours is another of the team's many projects. MicroRNAs are a type of regulatory molecule that generally act to switch off, or turn down, the expression of a gene or a set of genes. These recently discovered molecules have been found to play a regulatory role in many diverse biological processes. One recent bioinformatics project looked at a set of microRNAs in biological samples from childhood brain tumours versus normal tissue, to try to uncover whether particular microRNAs play a critical role in developing cancer. Research will continue in this area in 2012.



KIM CARTER AND  
RICHARD FRANCIS

For more information about our research in the area of BIOINFORMATICS, BIostatISTICS AND DATA SERVICES, visit [www.childhealthresearch.org.au](http://www.childhealthresearch.org.au)

Other projects in this area include:

#### Bioinformatics:

- FusionFinder - development of software to help identify known and novel gene fusions
- Investigating the relationship between severe infection in childhood and cardiovascular disease in later life using linkable population databases

#### Biostatistics:

- Genome Wide Association Studies looking at detecting associations between genetic variants and human disease
- Epidemiology of epilepsy
- Continuing analysis of a range of infectious disease studies
- Statistical support for key studies into mental health, Rett syndrome and Down syndrome

#### Data Services:

- Development of a database management system for the WA Autism Register
- Creation of online surveys and questionnaires for a variety of studies
- Management system development and support for research areas including Cerebral Palsy, Autism and Diabetes

# Research overview - CHILDREN'S CANCER AND LEUKAEMIA

## *Fighting the war against childhood cancer*

Our childhood cancer research teams are among the world's best, investigating childhood leukaemia and brain tumours from many angles to try and determine why cancer develops in certain children and how it grows.

Cancer is a devastating diagnosis, even more so when the patient is a child. While survival rates

for cancers such as leukaemia have improved immensely over the past 20 years - now up to 80 per cent - medical research still has a long way to go in determining the multiple factors that cause cancer and the best ways to treat, cure and ultimately prevent the disease from occurring.

Acute Lymphoblastic Leukaemia (ALL) is the most common childhood cancer - one in 2000 children are affected.

Our cancer epidemiology researchers look for patterns in population health data, including genetic, dietary and environmental risk factors that may lead to ALL in children. They collect their information using a variety of methods, from national and international databases, questionnaires, telephone interviews and blood and saliva samples.

In 2011, Dr Elizabeth Milne and her team found that children whose father smoked around the time of conception may have a 35 per cent higher risk of developing childhood leukaemia.

"The results fit with what we know about how tobacco smoke can damage the DNA in sperm, but these sperm are still able to fertilise an ovum," Elizabeth said.

She added that they found no increase for those who had previously smoked, suggesting that sperm with normal DNA may be produced after smoking is ceased.

"While women are often informed of the dangers to their unborn baby of smoking during pregnancy, this study shows that we also need to direct that message to potential fathers," she said.

Dr Milne urged caution in drawing a link in individual cases or laying blame.

"The causes of childhood leukaemia are likely to involve many interacting factors of which only one is cigarette smoking.

"However we do think it's important that potential fathers know the damage that may be caused to their sperm and have the opportunity to reduce that risk by stopping smoking."

Dr Milne's team is also analysing the results from a similar national study of childhood brain tumours.

In our cancer lab, researchers are looking at leukaemia, brain tumours and carcinoma in children, with a focus on why some children relapse or respond poorly to therapy. The team also investigates the underlying mechanisms in the development of paediatric brain tumours and ways to reduce their devastating impact.

In 2011, new research was published that outlined the best treatment options for children suffering from meningioma - a rare type of paediatric brain tumour.

Dr Rishi Kotecha, a researcher at the Institute and clinician at Princess Margaret Hospital for Children, diagnosed 17-month-old Rory with a

golf-ball sized meningioma tumour, something he had never seen before. The tumour is rare in children, it required an international search of the literature to find the best treatment.

The search found that aggressive surgical management is more likely to improve outcome and there was no benefit for the use of radiotherapy as initial treatment for meningioma in children. The findings could now help children all over the world.

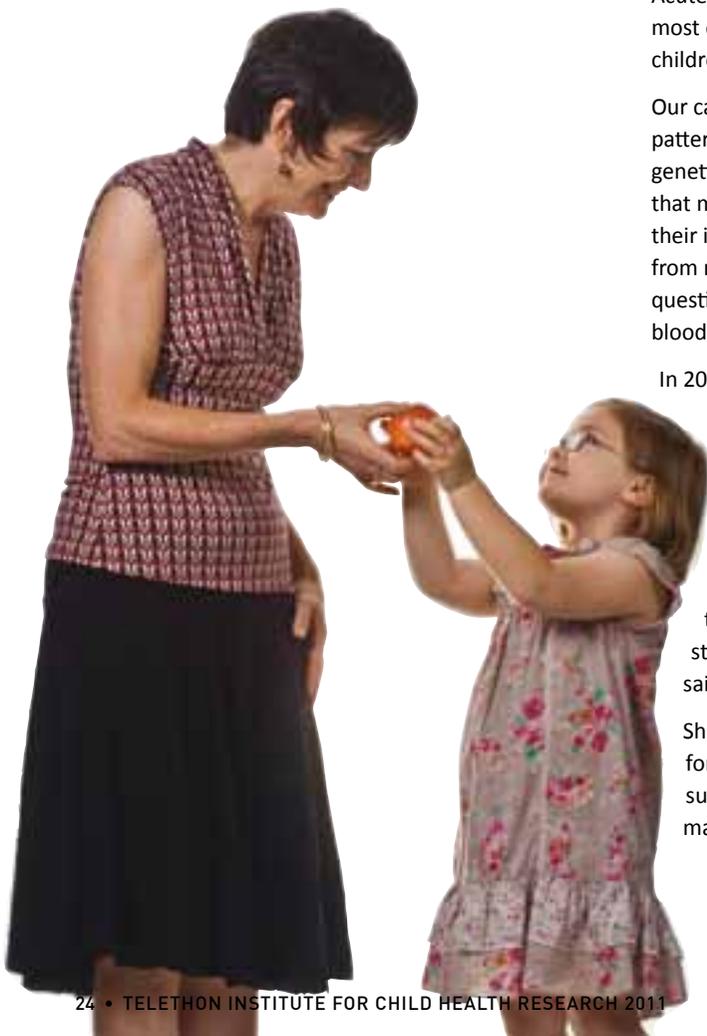
Our cancer research continues with the help of our dedicated supporters:

- Children's Leukaemia & Cancer Research Foundation
- The Telethon Adventurers

For more information about our research in the area of CHILDREN'S CANCER AND LEUKAEMIA, visit [www.childhealthresearch.org.au](http://www.childhealthresearch.org.au)

Other projects in this area include:

- Drug resistance leading to leukaemia relapse
- Acute lymphoblastic leukaemia in infants and the mixed lineage leukaemia (MLL) gene
- Improved therapy for a very aggressive carcinoma in children and adults
- International Case-Control Study into the causes of Embryonal Tumours



ELIZABETH MILNE WITH TULLY

## Research overview - CHILD DEVELOPMENT AND WELLBEING

### *Innovative language study gets green light to continue*

A child's ability to communicate is one of the most important developmental accomplishments and builds the foundation for success at school and beyond. The Institute's world-leading LOOKING At Language (LAL) study has been conducting in-depth assessments of language development since 2002 and has recently received the good news that its funding has been extended to 2017.

The LAL study is undertaken at the Telethon Institute for Child Health Research, in partnership with The University of Western Australia and the USA's University of Kansas

and University of Nebraska Medical Centre. The prestigious USA National Institutes of Health (NIH) has funded LAL since its inception in 2002 and will generously continue to do so to 2017.

This showcase project, studying the language development of more than 2000 WA children, is the world's only study to conduct such detailed assessment of language and literacy development from infancy to adolescence. The study has been tracking children at two, four, six and nine years of age. With news of another five years of funding, the children will be followed through to 14 years as they transition

through the formative adolescent years.

For the Institute, the ability to continue following the study children through early adolescence is ground-breaking.

"It is vitally important that we understand the developmental course of language and literacy from infancy and what different trajectories mean for young people's opportunities at school and beyond," said Site-Principal Investigator Professor Cate Taylor.

The ability to extend the assessments into the 14-year old age group will allow researchers to encourage more independent involvement from participants as they become teenagers. A new innovation will be to track pathways through school using internationally unique National Assessment of Literacy and Numeracy (NAPLAN) data available in Australia since 2008.

The extension will also ensure the ongoing close partnership between Institute researchers and Professor Mabel Rice from the University of Kansas. Professor Rice is the Principal Investigator on the LAL study and says the

opportunity to continue this work for another five years is truly remarkable.

Professor Rice said the extension will enable the study to focus on the children, with particular emphasis on twins, for much longer and in much more detail. This will allow researchers to achieve a rare insight into how the family structure, the inheritance pattern and other aspects of family life influence language and literacy development.

Professor Rice has also praised the outstanding work of the researchers at the Telethon Institute and the progressive and successful collaboration that is possible by the internationally recognised work being carried out here.

We thank the National Institute on Deafness and Other Communication Disorders (NIDCD) for their support.



CATE TAYLOR WITH TWINS  
ERIKA AND CHLOE

For more information about our research in the area of CHILD DEVELOPMENT AND WELLBEING, visit [www.childhealthresearch.org.au](http://www.childhealthresearch.org.au)

Other projects in this area include:

- Developmental Pathways in WA Children Project
- Determinants of child poverty in the US
- Australian Early Development Index
- ADHD

## Research overview - DATASETS AND COHORT STUDIES

### *Two decades of tracking child health and development*

They've been measured and examined since before birth. As babies, children, teenagers and young adults, they've been assessed on more than 10 separate occasions including having measurements of height, weight, skin folds and blood pressure, fitness testing, asthma and allergy tests, reading, counting, strength and posture. We've collected their teeth, saliva, blood and urine. We have more than 85,000 pieces of information on each one of them. For some, we also have over 2.5 million bits of genetic information.

They are the Raine Study kids, and they are part of the largest and longest running pregnancy and birth cohort study in the world.

In 1989, 2900 pregnant women were recruited into a research study at King Edward Memorial Hospital to examine ultrasound imaging.

The mothers were assessed at 18 weeks of pregnancy, then some again at 24, 28, 34 and 38 weeks of pregnancy. During this time, information was collected on the mother and father, such as diet, exercise, work and health.

Early findings from the study showed that repeated ultrasound scans in pregnancy are safe for mothers and their children with the children having normal postnatal growth, development, physical and mental health from birth through to young adulthood.

Over the years, the Raine Study has amassed one of the most unique and important collections of data in the world on demographic, developmental, psychological, physical and many other factors around the life of children and families. It is one of the few research studies where information was collected on the pregnant mother and then the child.

Other findings to come out of the Raine Study:

- an association between maternal smoking during pregnancy and low birth weight and high blood pressure in childhood and adolescence
- stressful events during pregnancy are associated with increased childhood and adolescent behavioural problems
- breastfeeding protects children from becoming overweight and obese in childhood and adolescence

- the introduction of milk other than breast milk before four months of age was a significant risk factor for asthma
- early viral infections and allergies are associated with the development of asthma in childhood and adolescence
- a high prevalence of back pain in adolescents with over 50 per cent of teenagers experiencing back pain.

All of the information collected over the years provides researchers with a better understanding of how events during pregnancy, as well as childhood and adolescence, affect later health and development.

The most recent follow-up has examined eye health and found 25 per cent of young adults have sun damage to their eyes. We're also

interested in reproductive health as these young adults start their own families.

In 2012, the cohort participants will be turning 23 years old and sharing their beauty sleep to add further research to the already extensive database.

Sleep is critical to health. On average, most people spend one quarter to one third of their life asleep. If sleep quality is poor it can affect many aspects of physical and mental health.

This will be the first time that sleep studies are performed on young healthy adults. The research will give us a better idea of sleep disorders in young people, an area that is still much of an unknown. Whilst many young adults do complain of restless and 'bad sleep', most sleep disorder diagnoses are made in the middle-aged population.



RAINE PARTICIPANT  
AMY WITH RESEARCH  
ASSISTANT DI WOOD

For more information about our research in the area of DATASETS AND COHORT STUDIES, visit [www.childhealthresearch.org.au](http://www.childhealthresearch.org.au)

Other projects in this area include:

- The Peel Study - Our Children, Our Families, Our Place: Enabling Communities for Child Health and Wellbeing
- WA Twin Child Health Study
- Western Australian Cerebral Palsy Register
- Western Australian Autism Biological Registry
- Population Health Research Network



# Research overview - DIABETES, OBESITY AND RELATED DISORDERS

## *Helping kids with diabetes*

Working to improve the lives of children and adolescents living with diabetes and obesity continues to be a key research focus at the Telethon Institute, with Dr Tim Jones' Diabetes and Obesity Research Team commencing or completing a number of significant clinical trials in 2011.

Research into Type 1 diabetes saw the start of a series of clinical trials aimed at investigating the use of pump therapy in the pursuit of a fully automated closed-loop system to help manage the disease. The study is looking at the effectiveness of diabetes pumps in detecting low blood sugar levels (hypoglycaemia) and their ability to automatically switch off insulin delivery as a way of reducing the severity of an episode of hypoglycaemia and subsequently reduce the burden of diabetes care.

2011 also saw the culmination of a series of clinical trials in collaboration with AIMedics Pty Ltd, aimed at assisting the development of a non-invasive monitoring system (HypoMon) for the detection of nocturnal hypoglycaemia. Fifty-two children and young adults with Type 1 diabetes mellitus took part in a blinded, in-clinic study to evaluate an alarm system aimed at recording overnight hypoglycaemic events.

The Adolescent Type 1 diabetes Cardio-renal Intervention Trial investigating the use of two types of medications (ACE inhibitors and statins) to prevent diabetes complications also progressed in 2011 with recruitment to this study due to close in June 2012. Some young people with Type-1 diabetes can go on to

develop kidney, eye and heart problems later in life and this international study is looking at the influence of these medications in helping adolescents shown to be at greater risk.

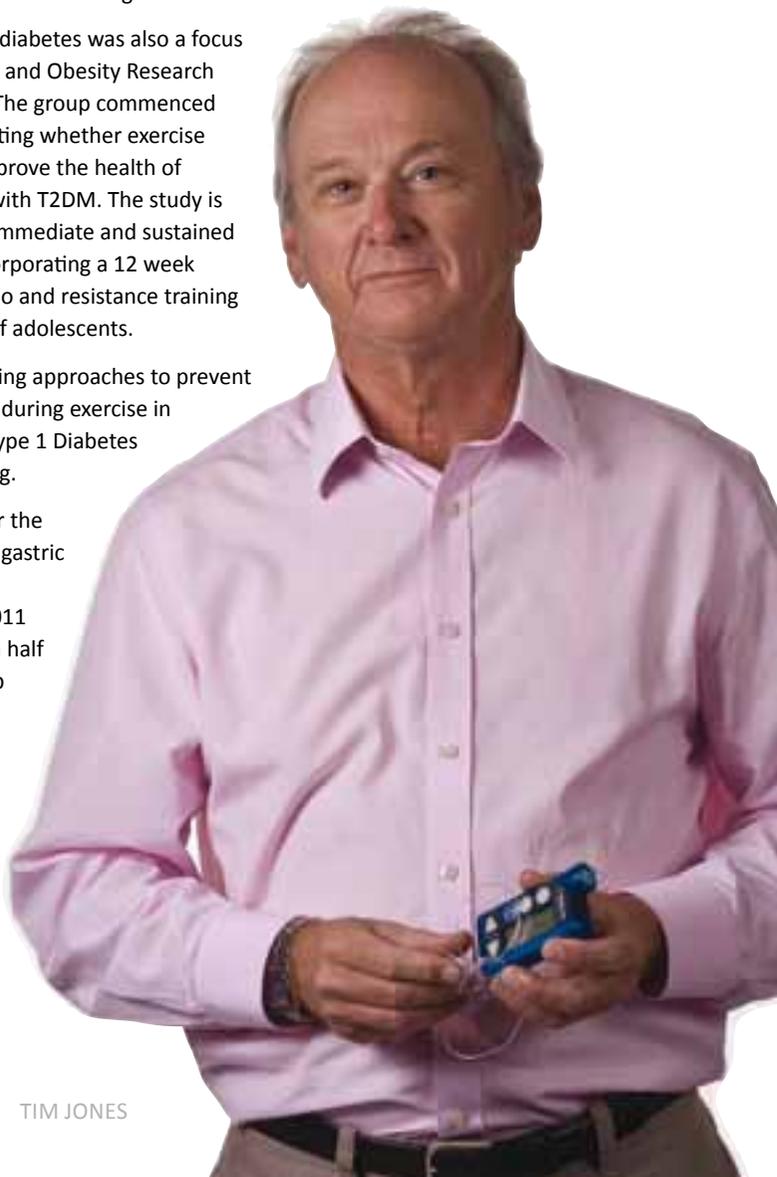
Type 2 (T2DM) diabetes was also a focus of the Diabetes and Obesity Research Team in 2011. The group commenced a trial investigating whether exercise training can improve the health of young people with T2DM. The study is looking at the immediate and sustained benefits of incorporating a 12 week combined cardio and resistance training on the health of adolescents.

Studies examining approaches to prevent hypoglycaemia during exercise in patients with Type 1 Diabetes are also ongoing.

Recruitment for the Bioenteric Intra-gastric Balloon study continued in 2011 with more than half the study group now on board. This research is aimed at investigating whether the use of gastric balloons in obese adolescents is effective

in weight loss, and whether it will assist in reducing the severity and frequency of obesity related problems.

The Institute research team works collaboratively with a range of key research groups including the Department of Endocrinology and Diabetes at Princess Margaret Hospital for Children, the School of Sports Science, Exercise and Health at UWA, the School of Psychology at UWA, the WA Institute for Medical Research, the Juvenile Diabetes Research Foundation and diabetes research centres interstate and overseas.



TIM JONES

For more information about our research in the area of DIABETES, OBESITY AND RELATED DISORDERS, visit [www.childhealthresearch.org.au](http://www.childhealthresearch.org.au)

Other projects in this area include:

- Low Glucose Suspend Study
- Epidemiology of Childhood Type 1 Diabetes
- Can exercise training improve health in young people with Type 2 diabetes?
- Randomised controlled trial of the Bioenterics Intra-gastric Balloon (BIB)
- Oral Insulin for prevention of diabetes in relatives at risk for Type 1 diabetes mellitus
- Adolescent Type 1 Diabetes Cardio-Renal Intervention Trial (AdDIT)
- Neurocognitive Outcomes of Children with Type 1 Diabetes Mellitus

# Research overview - DISABILITY AND DEVELOPMENTAL DISORDERS

## *Piecing together the autism puzzle*

From conception through childhood, our research into disabilities and developmental disorders encompasses any condition that disrupts 'typical' child development. This includes Autism Spectrum Disorders, a condition that affects up to one per cent of the population.

Autism Spectrum Disorder (ASD) is the umbrella term for neurodevelopmental disorders characterised by difficulties in social interaction and communication, and a restricted range of activities and interests. At one end of the spectrum, children will have severe social and communication impairment, often combined with an intellectual disability. At the other, children may have milder difficulties that do not prevent them from holding down a job or getting married. About 10 per cent of people with autism are "savants", with outstanding abilities in a particular area, most commonly maths.

Our Autism research team, led by Associate Professor Andrew Whitehouse, is at the cutting-edge of research and trials looking at the possible causes and risk factors associated with ASD, and how we can provide the best possible outcome for children and their families.

While we understand that autism runs in families, the exact causes of the condition remain unknown. Andrew's team is looking at the genetic and neurobiological causes of autism and related disorders, and are conducting clinical intervention trials into these conditions.

Our preliminary studies have already found that autism may be associated with two differences in development during pregnancy - enlarged head circumference and exposure to increased levels of testosterone.

With these encouraging findings, and one in every 100 people around the world affected by autism and the incidence increasing, researchers are working towards in-utero detection with intervention that starts at birth.

In a new study, we are comparing pregnancies in which the mother has had a previous child with autism (whereby the fetus is at increased genetic risk for autism) to pregnancies in which there is no family history of autism.

"Autism is not usually picked up until a child is between two and three years of age, often when a child is not meeting language milestones," Andrew said.

"If we could detect autism much earlier, we could start intervention when the course of the brain

development is much easier to alter. We're also hoping to provide extra training to child health nurses to help them identify warning-signs for autism at check-ups during the first year of life."

The study will also measure testosterone levels in the mother's blood and from umbilical cord blood, and closely monitor fetal growth to see if children with autism grow faster than other children.

Andrew's group is collaborating with scientists around the nation and internationally to try to find the cause and better treatments for the condition.

"Our knowledge of ASD has advanced considerably over the past decade as a result of the worldwide research effort," says Andrew.

Our team is taking a long-term approach towards establishing a strong ASD research program in WA that is closely integrated with ASD clinical services and also the training of future health care professionals providing services to affected children and their families so that kids on the spectrum lead a full and active life.



AMELIA AND MUM CAROLINE WITH RESEARCHERS  
JO GRANICH, ANDREW WHITEHOUSE AND ANNA HUNT

For more information about our research in the area of DISABILITY AND DEVELOPMENTAL DISORDERS, visit [www.childhealthresearch.org.au](http://www.childhealthresearch.org.au)

Other projects in this area include:

- Rett syndrome in Australia: AussieRett
- Language development
- IDEA - Intellectual disability exploring answers
- Down Syndrome
- International Study of Rett Syndrome: InterRett
- Birth anomalies
- Cerebral palsy
- Fetal Alcohol Spectrum Disorder
- Western Australian Autism Biological Registry

## Research overview - DRUG DISCOVERY

### *Translating research discoveries through commercialisation*

The strength of the Institute's Drug Discovery capabilities was exemplified with a breakout year for its first spin out company Phylogica.

Commercialisation remains one of the most effective ways of translating our research discoveries into results and the signing of new

contracts, and enhancement of existing ones, with international pharmaceutical and biotechnology companies signified a successful period for the company.

As the commercial arm of the Institute's Drug Discovery Technology Group, Phylogica signed its first multi-product agreement in late 2011 with Janssen, the pharmaceutical division of key multinational Johnson & Johnson.

Phylogica owns the world's most structurally diverse collection of unique natural peptide compounds known as 'Phylomers', which provide the foundation for its work in identifying new 'prototype' drugs. The Janssen collaboration will focus on the discovery of new peptides that can pull therapeutic cargoes through cell membranes of specific tissue types. This agreement marks a significant partnership aimed at investigating the potential development of new drugs targeting a range of diseases relevant to Janssen.

Collaborations with three other multinational companies, including Roche, Pfizer and Medimmune continued to strengthen in 2011 with key contract milestones achieved.

In further validation of the Institute's drug discovery program, Phylogica was also successful in expanding its already significant IP portfolio with a number of patents added to its extensive list in 2011.

This included the allowance of a new Australian patent covering methods of producing designed, synthetic libraries of peptides that are predicted to be rich in structure and therefore more likely to be drug-like than conventional random peptides. The allowance of this patent will add another powerful component to Phylogica's Phylomer platform and opens up new opportunities in the emerging field of synthetic biology.

The company now has 17 patent families including multiple cases which are granted in important global pharmaceutical markets such as Europe, Canada, the USA and Australia.

Phylogica's strategic collaboration with Cambridge University went from strength to strength in 2011. Their joint project 'Phenomica', which focuses on disease target discovery and validation using Phylomer peptides, drew attention from several pharmaceutical companies expressing interest in accessing the program's screening platform. A Pharma deal around access to this target discovery technology is expected in late 2012.

On the financial front the company has generated more than \$2 million in revenue from its Pharma partners and raised \$2.1 million in working capital from investors to finish with a strong balance sheet at the end of 2011. This, coupled with an increase in the number of invitations for representatives to present at significant and exclusive pharmaceutical and biotechnology conferences around the world, further reflected a quantum leap in Phylogica's global profile and reputation.



PHYLOGICA'S SARAH SEE AND RICHARD HOPKINS

For more information about our research in the area of DRUG DISCOVERY, visit [www.childhealthresearch.org.au](http://www.childhealthresearch.org.au)

## Research overview - ENVIRONMENTAL IMPACTS ON HEALTH

### *Making a difference in Nepal*

A child's development can be greatly affected by the physical environment in which they live and grow. Understanding the impact of influences such as diet, housing and pollution on a child's development is crucial in our efforts to combat the environmental hazards that can greatly inhibit their chance at a healthy life.

As part of its role as a World Health Organisation (WHO) Collaborating Centre for Research on Children's Environmental Health, the Institute is committed to researching environmental health influences in Australia and overseas. Part of that commitment has included a range of pioneering health initiatives and research in one of south Asia's most impoverished nations, Nepal.

In collaboration with Public Health Development Nepal, the Nepalese Ministry of Health and Population and the Kathmandu City Council, the Institute's team headed by Dr Merci Kusel has been instrumental in establishing a number of life-changing services and facilities including a free maternal and child health clinic, a pharmacy and a laboratory in one of Kathmandu's poorest slums.

The popularity of the clinic saw it cater for between 420 to 480 patients per month in 2011, offering a range of GP-style services including antenatal and postnatal care, immunisation, growth monitoring, family planning education and support, and general health checks.

Through Institute staff initiatives and fundraising, a pharmacy was also established in 2011 offering a range of free and discounted medications to assist with everyday healthcare and management. An

onsite laboratory was also set up to carry out a range of health and medical tests to support a community that is amongst one of the poorest in the world.

Throughout 2011 the groundwork was also laid for the establishment of a birthing centre to provide even more support to residents battling severe poverty and enormous health challenges in Nepal's inner city slums. The centre will open in 2012.

Planning also began for a mobile outreach clinic starting in 2012 that will offer additional health care services to three other Nepalese slums.

Crucial to achieving long term environmental health improvements in Nepal is a study being conducted by Institute researcher Tania Gavidia.

Research determining whether access to a maternal and child health clinic can improve the knowledge, attitudes and practices of women living in slum areas was established in 2011 and will continue for three years.

Additional support for improved services in Nepal also saw an important Institute initiative aimed at improving the knowledge and skills of local health care workers.

With the prevalence of asthma and respiratory lung disease increasing rapidly over the past decade in Nepal and a lack of routinely performed lung function tests, Institute researchers travelled to Nepal in April

2011 to run a five-day lung function training course at Kanti Children's Hospital.

Researchers, nurses, health technicians and doctors from a range of university and hospital departments attended the course. Future plans include field work to assess lung function in Nepalese school children to develop a reference standard for the community as well as prevalence studies of asthma and other respiratory diseases in the Nepalese community.



TANIA GAVIDIA

For more information about our research in the area of ENVIRONMENTAL IMPACTS ON HEALTH, visit [www.childhealthresearch.org.au](http://www.childhealthresearch.org.au)

Other projects in this area include:

- Kwinana Children's Respiratory Health Study
- Industrial air pollution and children's respiratory health
- Pre- and postnatal exposure to environmental pollution and children's health
- Parental occupational exposure to potential endocrine disrupting chemicals and risk of hypospadias in infants
- Arsenic in drinking water and chronic lung disease
- Diesel exhaust and respiratory health
- Geogenic dusts and lung inflammation
- Environmental exposures in remote indigenous communities

## Research overview - GENETIC IMPACTS ON HEALTH

### *Tackling a common illness from different angles*

Our researchers continue to lead the world in investigating genetic and other influences on complex infections and disease and one area of intense focus and progress is the fight against Otitis Media, or middle ear infection.

Otitis Media (OM) is among the most common illnesses of early childhood and can seriously affect language and learning development.

The Institute continues to target this disease on two key fronts investigating both the genetic impacts as well as environmental influences.

#### **Genetic studies**

The WA Family Study of Otitis Media reached a significant milestone in 2011 with 1000 children now taking part in the research project. Aimed at determining the role of genetics in OM, the study is collecting valuable information from families whose children have been recommended by Ear, Nose and Throat specialists to have grommets fitted due to recurring and severe ear infections.

The research team is using this large sample group to conduct the biggest genetic study of OM in the world looking at specific genes responsible for causing OM.

The team collaborate with many international research groups, one of which has identified a gene

that influences OM in animal models. The Institute team subsequently published research that showed the same gene influences the development of OM in children, knowledge that could provide a breakthrough into the cause and recurrence of severe ear infections and disease.

In another first for research into Otitis Media, the Institute team has also carried out a genome-wide analysis using data from the Raine Study. The research looked at DNA from more than 1500 participants to examine any common genetic links to Otitis Media and is expected to be published by mid-2012.

#### **Other OM studies**

In other work being done in OM, we are investigating the cause of OM in Aboriginal and non-Aboriginal children. In 2011, we conducted further evaluation of previously collected data as well as the ongoing development and implementation of innovative health promotional activities stemming from key research findings.

The high rates of OM in Aboriginal babies, often with no obvious symptoms, and the increased risk of OM with exposure to environmental tobacco smoke were targeted in an important cross-agency collaboration that saw a range of ear health initiatives rolled out. These included ear examinations of more than 200 Aboriginal children under the age

of five, and follow-up appointments as required at specialist Ear, Nose and Throat clinics.

Other initiatives include ways to reduce the spread of bacteria through frequent hand washing, music workshops with school children culminating in public performances of a musical promoting handwashing, promoting avoidance of tobacco smoke and encouraging regular ear checks.

For more information about our research in the area of GENETIC IMPACTS ON HEALTH, visit [www.childhealthresearch.org.au](http://www.childhealthresearch.org.au)

Other projects in this area include:

- Nutrition and genome health in children
- Epigenetics of hypospadias
- Family study of ear health and metabolic diseases in a WA Aboriginal community
- Genome-wide association study of visceral leishmaniasis
- Genetics and metabolomics at the interface between Type 2 diabetes and infection in Thailand
- Development of a vaccine against cutaneous and visceral leishmaniasis
- Comparative analysis of human and kangaroo leishmania

GRACE CHECKS OUT  
DEBORAH LEHMANN'S EARS



## Research overview - IMPACTS ON POLICY AND PRACTICE

### *No alcohol is the safest choice for mums-to-be*

Despite increased media coverage of alcohol-related health issues in Australia over the past year, low levels of awareness of the effects of drinking alcohol during pregnancy are still a major health concern.

CAROL BOWER  
WITH LUCA



With almost half of all pregnancies unplanned, the risk of unintentionally consuming alcohol within the first trimester is high and even once pregnant, many women are not aware that consuming alcohol can have life-long consequences for their child.

Our researchers are measuring the incidence in WA of the most serious of those consequences - children born with Fetal Alcohol Syndrome Disorders (FASD) or neurodevelopmental disorders, as a result of alcohol exposure in the womb.

The possible effects of fetal alcohol exposure include brain damage, birth defects, poor growth before and after birth, low IQ or learning difficulties, delayed development, social and behavioural problems and problems with hearing, speech and vision.

These children experience a range of symptoms that can include a delay in reaching milestones such as walking and talking; poor hand eye coordination; unable to complete complex tasks that involve planning, problem solving and judgement; and difficulties with motor function and social interactions. Children may also have poor academic performance and lack the ability to control their emotions.

Awareness and knowledge about the risks of prenatal alcohol exposure can assist women to make informed choices about their alcohol use during pregnancy.

Alcohol use in pregnancy is a sensitive issue and formative research is necessary to develop and

test messages about alcohol and pregnancy, targeting women who are pregnant and planning a pregnancy.

These health promotion messages will seek to promote healthy decisions and educate women about the risks to the fetus of prenatal alcohol exposure.

Our researchers have provided important evidence and advice to the National Health and Medical Research Council (NHMRC) during the revision of the Australian Guidelines to Reduce Health Risks from Drinking Alcohol. Guideline 4 deals with pregnancy and breastfeeding and now reads "For women who are pregnant or planning a pregnancy, not drinking is the safest option"

Much media attention over the past year has been focussed on the need for mandatory labelling of alcohol products. Using information from our research, the Institute has contributed to the labelling review on the need for appropriate evidence-based pregnancy warning labels.

We've contributed to the House of Representatives Standing Committee on Social Policy and Legal Affairs Inquiry into Foetal Alcohol Spectrum Disorder and the Education and Health Standing Committee Inquiry into improving educational outcomes for Western Australians of all ages (with a focus on FASD prevalence, prevention, identification, funding and treatment to improve education, social and economic outcomes).

The Institute is part of the newly-formed Alcohol Advertising Review Board, designed

to tackle head-on the alcohol-related issues in our society. Our Patron and Founding Director Professor Fiona Stanley will chair the Board which will consider and adjudicate complaints from the community about alcohol advertising, providing an independent alternative to Australia's current ineffective advertising self-regulation system.

For more information about our research in the area of IMPACTS ON POLICY AND PRACTICE, visit [www.childhealthresearch.org.au](http://www.childhealthresearch.org.au)

Other projects in this area include:

- Mandatory fortification of breadmaking flour with folate to prevent neural tube defects
- Developmental Pathways Project
- Development of a world first system for predicting the severity of asthma in young children
- Vaccine to prevent cervical cancer
- Juvenile diabetes DNA database
- Positive Parenting Program
- Swimming pools project
- WA Aboriginal Child Health Survey
- Newborn Hearing Screening
- Advisory Council on the Prevention of Deaths of Children and Young People

*Hope is what motivates us to work hard and get things done. It's the idea that something better will happen in the future because of what we do.*

- George Anderton



## Research overview - INFECTIOUS DISEASE

### *Continuing the meningitis fight*

The word 'meningitis' conjures up pretty scary thoughts for many parents. The disease progresses quickly and can have devastating effects. Knowing the signs and symptoms of meningitis and taking quick action can be the difference between life, permanent disability or death.

Meningitis is the inflammation of the meninges (the membrane lining of the brain and spinal cord). It usually refers to infections caused by viruses, bacteria, fungi, and other microorganisms such as parasites. Bacterial meningitis is life threatening and can cause death within hours, if not properly treated. There are many types of meningitis and whilst the symptoms are similar for each, the causes, treatments and outcomes do vary.

Since 1992, The Institute's Meningitis Centre has been raising awareness of meningitis, educating the community and advocating for life saving vaccines.

The Centre's Chairman Bruce Langoulant knows first-hand the devastating effects of meningitis. His daughter Ashleigh contracted the disease at six months of age and suffered severe brain damage leaving her with cerebral palsy and epilepsy, she is profoundly deaf, has never walked or talked and will rely on her family for day-to-day care for the rest of her life.

Ashleigh's story features in a video called *Two Lives, Two Different Outcomes*, along with AFL Premiership player Adam Selwood who contracted meningitis as a two-year-old and was fortunate to make a full recovery.

The video aims to raise awareness of the impact meningitis can have on individuals and their families.

For many years, our researchers have been involved in trials for vaccines against Meningococcal B, the last major cause of meningitis for which we don't have a vaccine. There are vaccines available that prevent meningococcal C, pneumococcal disease and Hib but a vaccine for Meningococcal B is still beyond our reach.

Our Vaccine Trials Group has been part of national and international trials of vaccines in young adults, adolescents and toddlers.

In 2011, adolescents aged between 11 and 17 years were asked to volunteer for a comparative study of two Meningococcal B vaccines manufactured at two different sites.

Study leader Dr Peter Richmond said the Meningococcal B strain of the bacteria accounts for more than 90 per cent of cases in WA.

"This is the last major cause of meningitis for which we don't have a vaccine and the one that most affects West Australians," said Dr Richmond.

"Meningococcal rates are higher in adolescents and very young children, so it's very important that we ensure that this vaccine is safe and effective in children."

Meningococcal infection can not only cause meningitis but several other serious diseases including septicaemia (infection of the bloodstream), infection of the joints, infection around the heart, and pneumonia.

The symptoms of meningococcal disease include fever, aches, chills and headaches. Infection can result in hospitalisation and even death in children and adults.

Despite treatment, there is a seven to 19 per cent death rate with any

type of meningococcal disease.

We were also pleased that studies of a combined Hib-meningococcal vaccine that have been conducted in toddlers over the last few years by the VTG, have led to the vaccine being approved for use in the National Immunisation Program to start in 2012. This will mean less injections for toddlers at 12 months of age.

For more information about our research in the area of INFECTIOUS DISEASE, visit [www.childhealthresearch.org.au](http://www.childhealthresearch.org.au)

Other projects in this area include:

- Pneumococcal disease (cause of meningitis, pneumonia and ear infections) in children and adults across WA
- Acute lower respiratory infections
- Hospitalisation for diarrhoea among WA children
- Whooping cough vaccine for newborns
- Cervical cancer vaccines
- Neonatal immunisation with pneumococcal conjugate vaccine in Papua New Guinea
- Influenza including swine flu and bird flu
- Otitis media (middle ear infections)
- Ross River virus
- Dengue fever
- Golden staph



PETER RICHMOND WITH ZEIKE

## Research overview - MENTAL HEALTH

### *Investigating eating disorders for prevention and early intervention*

An eating disorder is a serious mental illness, not a lifestyle choice, a diet gone wrong or a fad. An eating disorder is characterised when eating, exercise and body weight/shape become an unhealthy preoccupation of someone's life. Eating disorders include Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder and Eating Disorder Not Otherwise Specified (EDNOS).

The Institute's research on eating disorders is largely based on data collected from the Raine Study, one of the largest cohort studies in the world. Eating disorder symptoms were assessed in the Raine Study cohort at ages 14, 17 and 21 years.

Researchers have found that six per cent of the Raine Study cohort met full or partial diagnostic criteria for an eating disorder at age 14. An additional three per cent reported significant eating disorder symptoms without meeting criteria for an eating disorder diagnosis.

Dr Karina Allen said the strongest risk factors for developing an eating disorder by age 14 were being female and being perceived as overweight by one's parent(s) at age 10.

"Childhood social problems, low self-esteem relating to social situations, and having an overweight mother were also associated with an increased eating disorder risk," says Karina.

During 2011, the team has focussed on analysing the 17-year Raine Study eating disorder data. At this age, 10 per cent of the Raine Study cohort met full or partial diagnostic criteria for an eating disorder, representing a significant increase from the six per cent prevalence at age 14. As with the 14-year assessment, an additional three per cent of participants reported eating disorder symptoms that did not quite meet criteria for an eating disorder diagnosis.

Karina said that in the three years between assessments, around half of the teens with an eating disorder at age 14 no longer reported

significant eating disorder symptoms at age 17.

For those who continued to experience an eating disorder, other problem behaviours were reported.

"These teenagers were more likely to report difficulties with rule-breaking behaviour such as skipping school or using alcohol and they also reported significant difficulties in other areas, particularly in relation to depression," said Karina.

As teens, the most common forms of eating disorder were those that resembled bulimia nervosa, with binge eating and/or self-induced vomiting occurring in the absence of very low weight. Around 20 per cent of the participants with an eating disorder were male.

Dr Allen said the research team looked at neurocognitive functioning amongst 17-year old teens with an eating disorder.

"These teens showed poor performance on tasks requiring cognitive flexibility (being able to move between different tasks or different ways of processing information) and 'big picture' thinking (known as global processing)," said Karina.

"Studies in adult eating disorder patients have shown these sorts of neurocognitive deficits, but this is the first research to show these patterns in a population-based sample."

These sorts of cognitive difficulties may account for some of the symptoms characteristic of eating disorders, such as extreme rigidity in eating routines, attention to detail, and obsessive-compulsive traits."

With the 21-year Raine Study assessments wrapping up in 2012, the team will soon start analysing the eating disorder information collected, allowing the team to track eating disorder symptoms over a seven-year period. This is extremely rare in the eating disorder field and will allow researchers to focus on translating research outcomes into practical strategies to facilitate effective prevention and early intervention efforts for eating disorders.

For more information about our research in the area of MENTAL HEALTH, visit [www.childhealthresearch.org.au](http://www.childhealthresearch.org.au)

Other projects in this area include:

- "Looking Forward" Aboriginal Mental Health Project
- Human Capability project
- Breastfeeding and mental health
- Western dietary patterns in teenagers and behavioural problems
- Neck/spinal pain and depressive symptoms
- Biological mechanisms that may influence mental health outcomes in the Raine Study
- Social and lifestyle factors that may contribute to mental health
- Dietary intake of omega-3 fatty acids and depressive symptoms in adolescents
- Self-harm



KARINA ALLEN

## Research overview - PREGNANCY AND MATERNAL HEALTH

### *Mums-to-be urged to stress less*

Pregnancy is a unique time in a woman's life and a crucial time in determining the future health and wellbeing of the child. There are many factors during pregnancy that can influence the way in which the unborn child is programmed for future life outside the womb.

One of the areas we are looking at is the effect of stress during pregnancy on mental health outcomes in children.

Experiencing stress during pregnancy is common and can pose a threat to the developing child's later mental health and susceptibility to chronic and infectious disease.

But stress is difficult to define and

impossible to avoid. Stress during pregnancy is common for women across all social groups, educational backgrounds and ages. However, it is highly amenable to intervention and can successfully be managed and reduced.

Our current research looks not only at the effects of stress during pregnancy on the unborn child but also ways in which stress can be managed on a population-level which is particularly important for the modern pregnancy which takes place in an increasingly fast-paced and demanding environment for many women and their families.

Psychologist Dr Monique Robinson has been looking at stress during pregnancy and has found that the mother's experience of three or more stressful life events led to a significantly increased risk for behavioural problems in her child throughout childhood to early adolescence. This risk was present for stress both early and later in pregnancy.

"The type of stressful event experienced did not affect the increased risk," she said. "Both common problems such as money and relationship problems and rare events such as losing a job or death of a family member led to increased risk for behavioural problems."

Dr Robinson said apart from the fact that pregnancy and birth can often be experienced as stressful events in their own right, pregnancy also leads to a number of changes in the life circumstances of the mother and the family as a whole.

"This includes reduced work hours or even not working at all, helping children adjust to the arrival of a new baby sister or brother and the most common stress, the need to reassess and manage the family's financial situation," Dr Robinson said.

There is also the added stress of the perceived risks to both mother and child, the worry that serious complications or death could occur during the pregnancy or birth.

"Women are constantly warned about things that can go wrong during pregnancy: don't be too old, don't be too fat, don't eat soft cheese, don't eat pâté, don't drink alcohol, don't ride roller-coasters, don't live near the freeway – and on the list goes," says Dr Robinson.

"A stressful pregnancy is linked to an increased risk for postnatal depression. What we are concerned about is that the stress caused by over-estimating risks present during pregnancy may be causing more damage than the feared risks themselves."

Dr Robinson says the over-estimation of risk during pregnancy needs to be addressed, by both clinicians and researchers. The best way to do this through a trusting relationship with the obstetric care provider and communication of accurate pregnancy information.

She said there many ways that women can reduce stress during pregnancy.

"Techniques to help manage stress include focused deep breathing, spending time with friends and family, meditation, yoga, listening to relaxing music and light exercise," says Dr Robinson. "It's also important to seek help if things become overwhelming and keep a balanced perspective."

It is Dr Robinson's hope that this research can inform women to help make decisions about their pregnancy that may later lead to more positive physical and mental health outcomes for their children.



EXPECTANT MUMS THERESE,  
MELISSA AND KATHERINE

For more information about our research in the area of PREGNANCY AND MATERNAL HEALTH, visit [www.childhealthresearch.org.au](http://www.childhealthresearch.org.au)

Other projects in this area include:

- Pregnancy outcomes following assisted reproductive technologies (ART)
- Fetal Alcohol Spectrum Disorders (FASD)
- Overweight/obesity prior to pregnancy and depression
- Nutrition during pregnancy

# FACULTY AND PRE-FACULTY

The Faculty is the senior research leadership group of the Institute which includes Faculty and Pre-Faculty appointments. The group provides strategic advice to the Director on matters relating to research strategies and initiatives that promote and foster the conduct of high quality research (including research platforms and capabilities) across the Institute, the application of research, recruitment and retention of high quality researchers and the training of the next generation of research leaders. Researchers are appointed to Faculty by an external committee on the basis of sustained research performance.

The Pre-Faculty levels specifically acknowledge the challenges associated with moving into the Faculty and have been put in place to foster succession planning. Pre-Faculty appointments will meet some but not all of the required activities for Faculty and will be based on “potential” in addition to track record.

The Faculty also has a direct interface with the external Scientific Advisory Committee through the Biennial Faculty Retreat.

## FACULTY

### SENIOR PRINCIPAL INVESTIGATOR

Jenefer Blackwell  
Carol Bower  
Elizabeth Davis  
Nick de Klerk  
Prue Hart  
Patrick Holt  
Tim Jones  
Ursula Kees  
Deborah Lehmann  
Helen Leonard  
Fiona Stanley  
Stephen Stick  
Wayne Thomas  
Stephen Zubrick

### SENIOR PRINCIPAL PROGRAM MANAGER

Paul Watt

### PRINCIPAL INVESTIGATOR

Graham Hall  
David Lawrence  
Elizabeth Milne  
Wendy Oddy  
Roz Walker  
Andrew Whitehouse  
Graeme Zosky

### PROGRAM MANAGER

Sally Brinkman  
Kim Carter  
Richard Hopkins  
Tanyana Jackiewicz  
Glenn Pearson  
Cate Taylor



**JENEFER BLACKWELL**  
BSc(Hons) PhD FMedSci  
HonDSc(U.Khartoum) DSc(Cantab)

Research interests:

- Genetics and health
- Infectious diseases
- Metabolic diseases
- Tropical medicine
- Aboriginal health



**CAROL BOWER**  
MBBS MSc PhD FAFPHM DLSHTM FPHAA

Research interests:

- Birth defects
- Neural tube defects
- Alcohol in pregnancy
- Assisted reproductive technology



**ELIZABETH DAVIS**  
MBBS FRACP PhD

Research interests:

- Type 1 diabetes
- Type 2 diabetes
- Obesity



**NICK DE KLERK**  
BSc MSc PhD

Research interests:

- Epidemiological & biostatistical methods
- Epidemiology of respiratory diseases
- Health effects of air pollution, radiation and electromagnetic fields
- Research design
- Twin studies
- Clinical trials



**PRUE HART**  
BSc(Hons) MSc PhD

Research interests:

- Sunlight and immunity
- Vitamin D
- Macrophage regulation
- Inflammation control



**PATRICK HOLT**  
PhD DSc FRCPath FRCPI FAA

Research interests:

- Allergic and infectious diseases in the lung
- Immune regulation at mucosal surfaces
- Developmental immunology
- Pediatric vaccinology
- Improved strategies for asthma treatment and prevention
- Role of microbiota in disease susceptibility



**TIM JONES**  
MBBS DCH FRACP MD

Research interests:

- Type 1 Diabetes
- Hypoglycaemia
- Exercise and diabetes
- New diabetes therapies
- Diabetes complications
- Clinical trials



**URSULA KEES**  
Dip Phil II PhD

Research interests:

- Childhood leukaemia and cancers
- Molecular genetics of childhood malignancies
- Experimental models for cancer and leukaemia
- Development of diagnostic markers
- Improvement of therapy



**DEBORAH LEHMANN**  
MBBS MSc

Research interests:

- Infectious diseases
- Aboriginal health
- Pneumococcal disease
- Vaccination
- Otitis media
- Multidisciplinary research



**HELEN LEONARD**  
MBChB MPH

Research interests:

- Child disability
- Intellectual disability
- Autism spectrum disorders
- Down syndrome
- Rett syndrome
- Pre-term birth



**FIONA STANLEY**  
FAA FASSA MSc MD FFPHM FAFPHM FRACP  
FRANZCOG HonDSc HonDUniv HonMD  
HonFRACGP HonFRCPCH HonMD HonDSc

Research interests:

- Developmental pathways
- Aboriginal child health & wellbeing
- Population data & record linkage
- Evidence based policy for child health and wellbeing



**STEPHEN STICK**  
MB BChir PhD MRCP FRACP

Research interests:

- Paediatric respiratory disease
- Cystic fibrosis
- Respiratory epithelium
- Lung structure-function relation
- Health service delivery models



**WAYNE THOMAS**  
PhD

Research interests:

- Allergy
- Allergens
- Asthma
- Respiratory infection



**STEPHEN ZUBRICK**  
MSc AM PhD

Research interests:

- Social determinants of health
- Language development
- Child and adolescent mental health
- Human capital and capability
- Research translation into policy
- Aboriginal health and wellbeing



**PAUL WATT**  
BSc (Hons) D.Phil

Research interests:

- Drug discovery
- Inhibition of protein/protein interactions
- Construction & screening of peptide libraries
- Targeting biologics into cells
- Identification and validation of new candidate drug targets



**GRAHAM HALL**  
BAppSci, PhD, CRFS, FANZSRS

Research interests:

- Lung growth and development
- Cystic Fibrosis
- Pre-term birth and neonatal chronic lung disease
- Asthma
- Respiratory physiology
- Environmental health



**DAVID LAWRENCE**  
BSc PhD ATCL

Research interests:

- Physical health of people with mental illness
- Child and adolescent mental health
- Smoking, diet, nutrition, metabolism and obesity
- Aboriginal health
- Human capability expansion



**ELIZABETH MILNE**  
BSc PMH PhD

Research interests:

- Cancers in children and young adults: genetic and environmental risk factors
- Nutrition and DNA damage
- Genetic epidemiology
- Biological effects of folate
- Epidemiological methods

## FACULTY AND PRE-FACULTY



**WENDY ODDY**  
BAppSci MPH PhD

Research interests:

- Early nutrition
- Infant, child, adolescent and maternal nutrition
- Developmental origins of health and disease
- Nutritional determinants of health and disease



**ROZ WALKER**  
BA(Hons) PolSci PhD Phil

Research interests:

- Aboriginal health and wellbeing
- Social determinants of health
- Early years development
- Cultural competence
- Community engagement
- Mixed methods research



**ANDREW WHITEHOUSE**  
BSc(Hons) PhD

Research interests:

- Autism
- Developmental disorders
- Prenatal exposures
- Cognitive and language development
- Randomised controlled trials



**GRAEME ZOSKY**  
PhD MBiostat

Research interests:

- Lung growth
- Respiratory environmental health
- Lung function
- Asthma



**SALLY BRINKMAN**  
BA MPH

Research interests:

- Early child development/education
- Teenage pregnancy
- Culture and family practices
- Population monitoring
- Evaluating interventions/programs
- Research translation



**KIM CARTER**  
BSc PhD

Research interests:

- Bioinformatics
- Genetics and Genomics
- Databases
- Research data sharing techniques
- Data visualisation



**RICHARD HOPKINS**  
BSc (Hons) PhD

Research interests:

- Drug discovery
- High throughput screening
- Rationale-based drug design
- Cell penetrating peptides to deliver therapeutic cargoes
- Antimicrobial peptide discovery



**TANYANA JACKIEWICZ**  
BSc(Hons) MPH

Research interests:

- Health and wellbeing of vulnerable children and families
- Research translation into policy
- Evaluation of early years and suicide prevention programs
- Support for government to deliver evidence-based programs



**GLENN PEARSON**  
BA(Education)

Research interests:

- Aboriginal health
- Infectious diseases
- Mental health
- Intercultural studies
- Action research



**CATE TAYLOR**  
BAppSci PGDip PhD FSPAA

Research interests:

- Language acquisition
- Literacy Acquisition
- Educational achievement
- Developmental trajectories
- Twins
- Early language and literacy promotion

You can read bios for each of our Faculty members on our website:

[www.childhealthresearch.org.au](http://www.childhealthresearch.org.au)

## PRE-FACULTY

### ASSOCIATE PRINCIPAL INVESTIGATOR

Alex Beesley  
Anthony Kicic  
Shelley Gorman  
Alexander Larcombe  
Monique Robinson  
Deborah Strickland

### ASSOCIATE PROGRAM MANAGER

Tatjana Heinrich  
Katrin Hoffman  
Clair Lee  
Nadia Milech



**ALEX BEESLEY**  
BSc(Hons) PhD

Research interests:

- Cancer biology
- Drug resistance
- Genomic technologies
- Novel therapies



**ANTHONY KICIC**  
BSc(Hons) PhD

Research interests:

- Epithelial injury/repair in childhood asthma, cystic fibrosis and lung transplantation
- Viruses and childhood inflammatory respiratory diseases
- Epithelial barrier function
- Lung transplant rejection
- Stem cells and the lung



**SHELLEY GORMAN**  
BSc(Hons) PhD

Research interests:

- Sunlight, vitamin D and immunity
- Ultraviolet radiation
- Topically-applied vitamin D
- Allergy and asthma
- Skin disease
- Obesity-induced metabolic disease



**ALEXANDER LARCOMBE**  
BSc(Env)Hons PhD

Research interests:

- Lung growth and development
- Environmental health
- Asthma and allergy
- Respiratory viral infection



**MONIQUE ROBINSON**  
PhD MPsych(Clinical) MAPS

Research interests:

- Child mental health
- Perinatal mental health
- Pregnancy
- Developmental origins of behaviour



**DEBORAH STRICKLAND**  
PhD

Research interests:

- Allergic disease models
- Inflammation/infection
- Immunology; dendritic cells, T cell populations
- Early origins of disease
- Immunotherapy



**TATJANA HEINRICH**  
BSc(Hons) PhD

Research interests:

- House dust mite allergy
- Desensitisation
- Antibiotic resistance in gram-negative bacteria
- Antimicrobial peptides
- Peptide display libraries in Bacteriophage
- Drug discovery



**KATRIN HOFFMAN**  
PhD

Research interests:

- Peptide-based drug discovery and therapeutics
- Phage display technology
- Protein engineering
- Cell-penetrating peptides
- Peptide-based vaccines
- Peptide libraries



**CLAIR LEE**  
BSc PhD

Research interests:

- Cystic fibrosis
- Clinical trials
- Translational medicine
- Research governance
- Project management



**NADIA MILECH**  
BSc(Hons) PhD

Research interests:

- Research translation
- Peptides as biologic drug leads
- Targeting intracellular proteins & interactions
- Phenotypic & intracellular screen development
- Ischaemia, inflammation and cancer
- Neurotrauma and brain tumours

## Research Leadership Program

In collaboration with Organisational and Staff Development Services at The University of Western Australia, the Institute has developed an innovative leadership development program with the aim of nurturing our next generation of research leaders.

Institute researchers were invited to nominate for the one-year program and nominations were judged by an independent committee. After a rigorous decision-making process, the inaugural Research Leadership Team was chosen, made up of 10 early to mid career researchers who demonstrate outstanding leadership potential.

- Dr Alex Beesley (Leukaemia and cancer research)
- Associate Professor Graeme Zosky (Lung growth and respiratory environmental health)
- Professor Graham Hall (Paediatric respiratory physiology)
- Associate Professor Andrew Whitehouse (Developmental disorders)
- Dr Deborah Strickland (Respiratory immunology animal research program)
- Dr Anthony Bosco (Asthma and allergy)
- Dr Belinda Hales (Infection and asthma and allergy)
- Dr Melissa O'Donnell (Child abuse and neglect)
- Associate Professor Chris Peacock (Genomics and infectious disease)
- Dr Raelene Endersby (Leukaemia and cancer research)

The Research Leadership Program comprises 360 degree leadership profiling (leadership styles inventory); support for interstate mentoring; a variety of workshops, including media, communications and finance management; career management strategies; leading and managing research groups; and peer support. A residential program was held in November 2011, including a presentation by Professor Fiona Stanley to the group 'Reflections on leadership - conditions for success'.

Members of the Research Leadership Team have met with a number of outstanding community and political leaders to hear first-hand about their leadership journey and to understand, what they feel are the important characteristics of leadership. This included the Hon Julie Bishop MP and Minister John Day.

Over the past year, Research Leadership Team members have participated in leadership development projects that have contributed to the growth of the Institute as a whole. These projects were selected by the participants and included development of a new campus-wide Child Health Research Seminar Series; development of the internal grant review process for NHMRC project grant submissions; and development of a new model for higher degree research student training.

Throughout the year, team members were also invited to represent the Institute at high profile corporate functions and meet key corporate and individual donors.

Team member, Dr Melissa O'Donnell, says the program has greatly assisted her to develop the skills required of a research leader.

"The program has enabled me to reflect on my own performance from the perspectives of my colleagues and students whom I supervise, so that I can consolidate my strengths and develop on areas of weakness," Melissa says.

"The course has also helped me to focus on my short and long term research goals and to work and communicate with my team more effectively."

Proving a successful model in its first year, the

research leadership program has contributed to supporting leadership development, succession planning strategies and Institute-wide peer support. Individual team members have demonstrated outstanding commitment to the Institute, with their contributions greatly benefiting the wider Institute community as well as their own careers. The program will be conducted again in 2012/13.



LEFT TO RIGHT: STANDING, MELISSA O'DONNELL, ANDREW WHITEHOUSE, RAELENE ENDERSBY, ALEX BEESLEY, BELINDA HALES, FIONA STANLEY, ANTHONY BOSCO, DEBORAH STRICKLAND, MOIRA CLAY. KNEELING, GRAHAM HALL, GRAEME ZOSKY, CHRISTOPHER PEACOCK, KATHY VIAL.

*Hope.....for a healthier future*





## Supporting researchers and students

### Postdoctoral Researchers Group

Born out of a desire to provide a voice for early and mid-career researchers, the Institute's Postdoctoral Research Group (PRG) continued to make an impact in 2011 with significant input into key Institute policy and planning.

Established in 2008 to support postdoctoral scientists in the progression of their careers, one of the group's main achievements in 2011 was to provide valuable advice and feedback on the design of the Institute's research career path framework. The PRG's input was a key factor in the development of the 'Pre-Faculty' levels of Associate Principal Investigator and Associate Program Manager. These levels specifically acknowledge the challenges associated with moving into the Faculty and have been put in place to foster succession planning and development of the next generation of research leaders.

Founding group member and 2011 Deputy Chair Graeme Zosky says the group has gone from strength to strength over its short history and while it is primarily focused on fostering the development of early to mid-career researchers, its work and decisions have a positive impact across the whole Institute.

"The PRG is a crucial middle tier within the Institute and by working with a range of groups, from assisting the students to having strategic input at management level, we are fortunate to be able to work with, and provide feedback to, people right across the whole organisation." says Graeme.

Other achievements over the past year include efforts to re-energise the Institute's seminar series, with added input into visiting speakers and increased promotion and support for the event.

The PRG also began initial planning and development for the inaugural Early Career Researchers Retreat to be held in June 2012.

Thanks to the Postdoctoral Research Group Committee - Dr Sarra Jamieson (Chair), Associate Professor Graeme Zosky (Deputy Chair), Dr Deborah Strickland, Prof Moira Clay, Ms Kathy Vial, Associate Professor Andrew Whitehouse, Dr Peter Dallas, Dr Rebecca Glauert, Associate Professor Kim Carter, Dr Belinda Hales, Dr Katherine Thompson, Dr Monique Robinson and Dr Nadia Milech.

### Student Circle

The Telethon Institute Student Circle aims to develop confident and capable researchers of the future. The group is made up of postgraduate students at the Institute, and from the School of Paediatrics and Child Health at UWA and other postgraduate students based at PMH. They include honours, masters and PhD students.

Committee member Kitty Foley says the aim of the Student Circle is to be a voice for student issues within the Institute.

"We also want to provide a sense of community and togetherness for the students, and play a



THE STUDENT GROUP AT THE INAUGURAL STUDENT CIRCLE DEVELOPMENT PROGRAM HELD AT ROTTNEST ISLAND

role in 'giving back' to the community," says Kitty.

With this in mind, the organisers of the Student Circle are also part of the Student Reference Group (SRG), a group responsible for student training and affairs at the Institute.

Students meet monthly to discuss career development, training courses, workshops, funding opportunities, upcoming guest speakers, as well as numerous other important aspects of student life within the Institute community.

During 2011, the Student Circle updated the image of the group with a new logo and new corporate sponsors.

April 2012 saw the launch of the Inaugural Student Circle Development Program, held on Rottnest Island. The weekend's program included a number of experts including representatives from a range of science areas who presented on their research and provided some insight into

their career journeys.

In organising the weekend's activities, committee member Stephanie Fehr said they wanted the invited speakers to inspire and motivate the students.

"It's always great to hear how successful people have come to be where they are, the choices they made along the way and useful advice they might have for those at the beginning of the journey," says Stephanie.

Incoming Director of the Institute, Jonathan Carapetis, and current Acting Director, Moira Clay, participated in an informal Q&A session over dinner, allowing the students to ask about future opportunities both for the Institute as a whole, and their own career paths.

Thanks to the Student Circle Organising Committee - Stephanie Fehr, Kitty Foley, Alex Heaton (SPACH) and Ashley Schoof.

# COLLABORATIONS

Researchers at the Telethon Institute have forged strategic collaborations with researchers in their fields at major universities and institutes around the world.

Some of our key collaborations are listed below.

## International

Addenbrooke's Hospital (UK)  
Bern University Hospital (Switzerland)  
Brigham and Women's Hospital (USA)  
Cambridge University (UK)  
Canadian Institute Health Research (Canada)  
Centro Médico Teknon and Sant Joan de Déu Hospital (Spain)  
CESP Centre for Research in Epidemiology and Population Health (France)  
Children's Oncology Group (USA)  
Children's Research Institute (USA)  
Columbia University (USA)  
Erasmus University (The Netherlands)  
Fox Chase Cancer Center (USA)  
Harvard Medical School (USA)  
Hospital for Sick Children (Canada)  
Hospital Geral de Santo Antonia (Portugal)  
Institute for Child Health (UK)  
Institute of Psychiatry (UK)  
Instituto Nacional do Cancer (Brazil)  
International Agency for Research on Cancer (France)  
Israeli Rett Centre (Israel)  
Karolinska Institute (Sweden)  
Kennedy Krieger Institute and Johns Hopkins

University School of Medicine (USA)  
Lead Discovery Centre GmbH (Germany)  
Louisiana State University (USA)  
Mcgill University & Centre Universitaire Mere-Enfant Sainete-Justine (Canada)  
McMaster University (Canada)  
Morgan Stanley Children's Hospital of New York (USA)  
Mount Sinai School of Medicine (USA)  
National Heart & Lung Institute (UK)  
National Institute for Rare Diseases Research (Spain)  
National School of Public Health, Oswaldo Cruz Foundation (Brazil)  
Norwegian Institute of Public Health (Norway)  
Papua New Guinea Institute of Medical Research (Papua New Guinea)  
Peking University First Hospital (China)  
Respiratory Sciences Center, University of Arizona (USA)  
Safra Pediatric Hospital (Israel)  
St Jude Children's Research Hospital (USA)  
Swedish Rett Centre (Sweden)  
Swiss Institute of Allergy and Asthma Research (Switzerland)  
The International Foundation for CDKL5 Research (USA)  
THL National Institute for Health and Welfare (Finland)

Turku University (Finland)  
Upper Airway Research Laboratory (Belgium)  
University of Aarhus (Denmark)  
University of Alabama (USA)  
University of Athens (Greece)  
University of California (USA)  
University College London (UK)  
University of Edinburgh (UK)  
University Hospital of South Manchester (UK)  
University of Kansas (USA)  
University of Leicester (UK)  
University of Manitoba (Canada)  
University of Minnesota (USA)  
University of Nebraska Medical Centre (USA)  
University of Otago (New Zealand)  
University of Szeged (Hungary)  
University of Vienna (Austria)  
University of Waterloo (Canada)  
University Of Wisconsin Medical School (USA)  
University of York (UK)  
Wellcome Trust Sanger Institute (UK)  
Yunnan University Population Research Institute (China)





## Australian

- Alfred Hospital (VIC)
- Australian Clinical Trials Network (NSW)
- Australian Institute of Family Studies (VIC)
- Australian National University (ACT)
- Central Queensland University (QLD)
- Children's Cancer Institute Australia for Medical Research (NSW)
- Charles Sturt University (NSW)
- Children's Hospital Westmead (NSW)
- Curtin University (WA)
- Edith Cowan University (WA)
- Flinders University (SA)
- Griffith University (QLD)
- Hunter Medical Research Institute (NSW)
- John Hunter Hospital (NSW)
- King Edward Memorial Hospital (WA)
- Kolling Institute of Medical Research (NSW)
- Lions Eye Institute (WA)
- Mater Children's Hospital (QLD)
- Menzies School of Health Research (NT)
- Monash Medical Centre (VIC)
- Monash University (VIC)
- Murdoch Children's Research Institute (VIC)
- Ngunytju Tjitji Pirni Inc (WA)
- Princess Margaret Hospital for Children (WA)
- Queensland Children's Medical Research Institute (QLD)
- Queensland University of Technology (QLD)
- Royal Children's Hospital (QLD)
- Royal Children's Hospital Melbourne (VIC)
- Royal Darwin Hospital (NT)
- Royal Hobart Hospital (TAS)
- Royal Perth Hospital (WA)
- Sir Charles Gardner Hospital (WA)
- Sydney Children's Hospital (NSW)
- The Rural Clinical School of WA (WA)
- University of Adelaide (SA)
- University of Melbourne (VIC)
- University of Queensland (QLD)
- University of Sydney (NSW)
- University of Tasmania (TAS)
- University of Technology Sydney (NSW)
- University of Western Australia (WA)
- Walter and Eliza Hall Institute of Medical Research (VIC)
- Western Australian Institute of Medical Research (WA)
- Westmead Hospital (NSW)
- Women's and Children's Hospital (SA)



*When the world says, "Give up,"  
Hope whispers, "Try it one more time."*

*– Anonymous*

# CONSUMER AND COMMUNITY PARTICIPATION

The consumer and community engagement program at the Institute continued to develop throughout 2011 with a long list of activities and achievements aimed at increasing consumer involvement in our research programs. Jointly operated with the University of Western Australia's School of Population Health, this unique and successful program is made possible through the ongoing input and support of researchers, consumers and community members.

## Consumer and Community Advisory Council

The Consumer and Community Advisory Council continued to meet in 2011 kicking off with a planning session to discuss ways of increasing the Council's profile across the Institute.

- The Council was active in the 'Discoveries Needs Dollars' campaign to lobby the Australian government for appropriate funding for health and medical research. Council members sought support from their networks asking them to email, write letters, contact parliamentarians and take part in the Perth Rally. This was an outstanding success with the campaign organisers acknowledging the support from WA consumers and community members.
- The 'Consumer and Community Participation Award' for 2011 was presented to Deborah Lehmann, Hannah Moore and Kirsten Alpers for their ongoing commitment to facilitating consumer and community participation within the Infectious Diseases research area.
- Council members were involved in providing a community perspective to the Institute's grant application and review process that was developed in 2011 with the inclusion of a community member on the review panels.

- The Council had its 20th meeting in December with a celebratory morning tea with Institute Director Professor Fiona Stanley to express thanks for her ongoing support for the Council.

## Consumer and Community Participation Unit

The joint Telethon Institute and UWA School of Population Health consumer and community participation program received a boost in 2011 with continued funding to enable the unit to develop a range of support materials and programs.

- Hayley Haines joined the Unit as a Project Officer.
- A series of Fact Sheets aimed at providing researchers with short, simple 'tools' to support the implementation of consumer and community participation in health research.
- A new website to enhance the Unit's national and international profile.
- Planning for a 'Participation Network' which will see the establishment of a database of community members willing to provide community advice and perspective to a range of projects across the Institute.

## Developmental Pathways Project

A key initiative aimed at assisting and guiding the ARC Developmental Pathways Project (DPP) was the establishment of a 16 member community reference group. The group, which met for the first time in December, was put in place to provide a community perspective on this important, data-linkage project.

The reference group will provide an oversight role for the project's governance, standards and practices with a focus on the community's understanding and perception of linked data.

## Researcher training workshops

A series of workshops, aimed at providing training support for researchers, were held throughout 2011.

- Researchers in the Institute's Program Grant attended training sessions facilitated by our consumer advocate Anne McKenzie and Bec Hanley (a UK consumer advocate).
- Anne and Bec ran two workshops at the Australian National University in May, attended by 40 people.
- Three workshops were held for the Population Health Research Network which is hosted by the Telethon Institute.



KIRSTEN ALPERS, JULIE IRELAND, HANNAH MOORE AND DEBORAH LEHMANN

## Community Conversations

Aimed at informing consumers and community members about current research projects a number of conversations were held in 2011 including:

- Two Fetal Alcohol Spectrum Disorders (FASD) community conversations in Perth and Cairns to gain community feedback on a screening and diagnostic tool for FASD.
- A community conversation on immunisation consent as well as the information needed by parents to help them make informed immunisation choices.
- A forum for parents of children with cerebral palsy about proposed legislative changes to the West Australian Developmental Anomalies Register.



*Hope....for a discovery*

# ABORIGINAL COLLABORATIVE COUNCIL ADVISING ON RESEARCH AND EVALUATION

The Aboriginal Collaborative Council Advising on Research and Evaluation (ACCARE) is the Aboriginal 'lens' to guide, support and provide Aboriginal knowledge and wisdom to ensure the integrity of Aboriginal philosophies and way of life is embraced by researchers to improve Aboriginal health and wellbeing.

The end of 2011 saw Rhonda Marriott, a leading pioneer of ACCARE, step down from the role of Chair. Mrs Leslie-Ann Conway, Executive Manager of the Nganytju Tjitji Pirni Aboriginal Corporation in Kalgoorlie replaces Rhonda as Chair.

Under Rhonda's leadership, ACCARE has grown in profile to be seen as a key advocate for Aboriginal research, actively working with community partners to foster new research opportunities and pathways for Aboriginal students and researchers.

"It has been a privilege to lead ACCARE over the last two years and to support over 40 different research presentations ranging from ante-natal services to organ donation," Rhonda said.

Other achievements during this time include launching the Warburton Women Breakfast Book with the Minister for Education, supporting the creation of the ACCARE "Symbol of Collaboration" logo, and the setting up of strategic communication channels including a newsletter, brochure and the redesign of the Aboriginal Health website.

Rhonda knows ACCARE will only get stronger under the leadership of Leslie-Ann Conway.

"Leslie-Ann has extensive experience in advocating for Aboriginal issues and is passionately committed to ensuring a high level of service delivery to Aboriginal

communities," Rhonda said.

Professor Fiona Stanley, Patron of Telethon Institute, thanked Rhonda for her tireless commitment to leading ACCARE over the past few years.

"It has been due to the unwavering dedication of Rhonda and the Council members which has resulted in ACCARE being seen as a model of best practice," Fiona said.

Acting Director Moira Clay acknowledged the contribution ACCARE provides to the broader community.

"The Institute and the Board strongly support ACCARE and recognise the Council's broad community representation, expertise and involvement will ensure that the research conducted through the Telethon Institute will meet Aboriginal research priorities," Moira said.

With this strong support and encouragement, Leslie-Ann and Council members are eager to ensure the facilitation, translation and application of research findings into policy and practice will improve health and wellbeing outcomes for Aboriginal families.

Among its many mandates, ACCARE will continue to provide a forum for state-wide representation, consultation and dissemination of information as a result of Aboriginal Research conducted by the Telethon Institute.

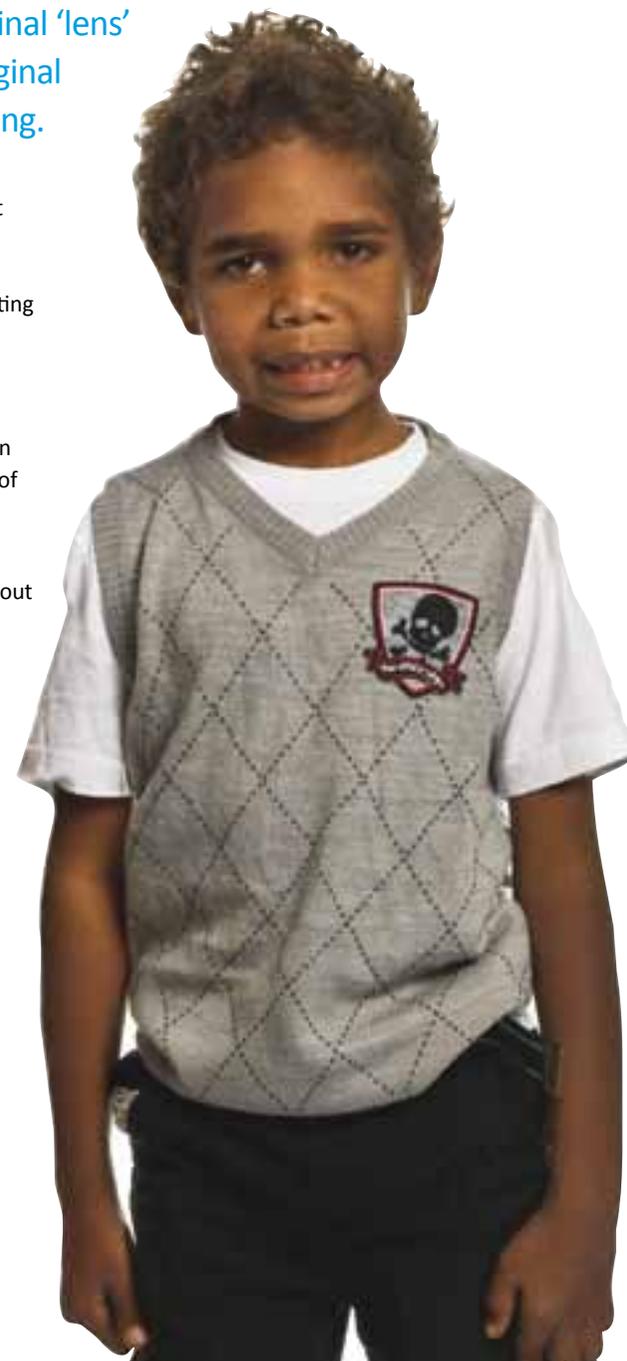
ACCARE will also actively identify, support and foster new research opportunities for Aboriginal research and Aboriginal researchers and assist in maintaining existing collaborations with local and regional committees and organisations.

In 2012, the Council will provide support and direction to Institute researcher Glenn Pearson who is leading the development of the Institute's five-year Aboriginal health strategic plan.

The ACCARE Council is always on the lookout for new opportunities for partnering with key external organisations or networks.

Membership of the ACCARE is well represented across Western Australia by a strong contingent of Aboriginal and non-Aboriginal people through their involvement in the health sector and as representatives of the Aboriginal community.

For further information visit [aboriginal.childhealthresearch.org.au](http://aboriginal.childhealthresearch.org.au)



## NEW BUILDING PROJECT

### *Institute's new home taking shape*

2011 marked a significant leap forward in the Institute's planned move to its future home within the new children's hospital, with the unveiling of concept drawings and designs for the \$1.2 billion dollar development on the QEII complex site.

The Telethon Institute is expected to move into the state-of-the-art premises in early 2016 and its dedicated planning team was kept busy in 2011 ensuring the Institute had input into the decision making process for the new building that's aimed at providing increased space and access to leading-edge technology and research facilities.

The Institute will retain its own area and its own identity within the new children's hospital, but is also proud to be a part of an Integrated Research and Education Facility (IREF) that will enable our world-renowned researchers to work alongside some of this state's most innovative and progressive child health clinicians. This will ensure strong and progressive collaboration in the fight against childhood illness and disease.

Initial work also began on the Institute's design of research areas and individual departments and this is continuing into 2012.

Funding for the innovative and exciting new Telethon Institute is being generously provided by both the WA State government and the Australian government.



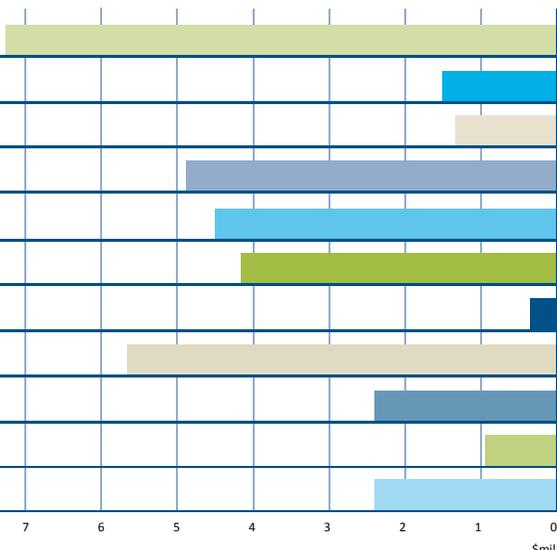
INITIAL CONCEPT DRAWINGS FOR THE NEW CHILDREN'S HOSPITAL PROJECT WHICH WILL INCLUDE THE TELETHON INSTITUTE BUILDING



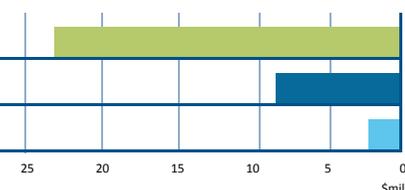
*Hope.....for health*

# 2011 - THE YEAR IN BRIEF

INCOME	Amount	%
Australian competitive grants	7,291,178	20.6
International competitive grants	1,445,909	4.1
Other competitive grants	1,324,272	3.8
Government contracts	4,905,034	13.9
Commercial income	4,507,108	12.8
Other grants	4,221,372	11.9
Miscellaneous income	322,871	0.9
Donations, fundraising & bequests	5,653,440	16.0
Investment income	2,380,356	6.7
Realised gain on investments	933,646	2.6
Research support	2,376,356	6.7
Gross income	35,361,542	100
Deferred income	(682,761)	
Net Income	34,678,781	



EXPENSES	Amount	%
Scientific research	23,164,473	68.0
Research administrative and building services	8,607,655	25.2
Depreciation and provisions	2,307,200	6.8
Total	34,079,328	100



PROFIT 599,453

## Staff and students

Total number of staff as at December 31 (paid and seconded) - 351

Total number of postgraduate students during the year - 94

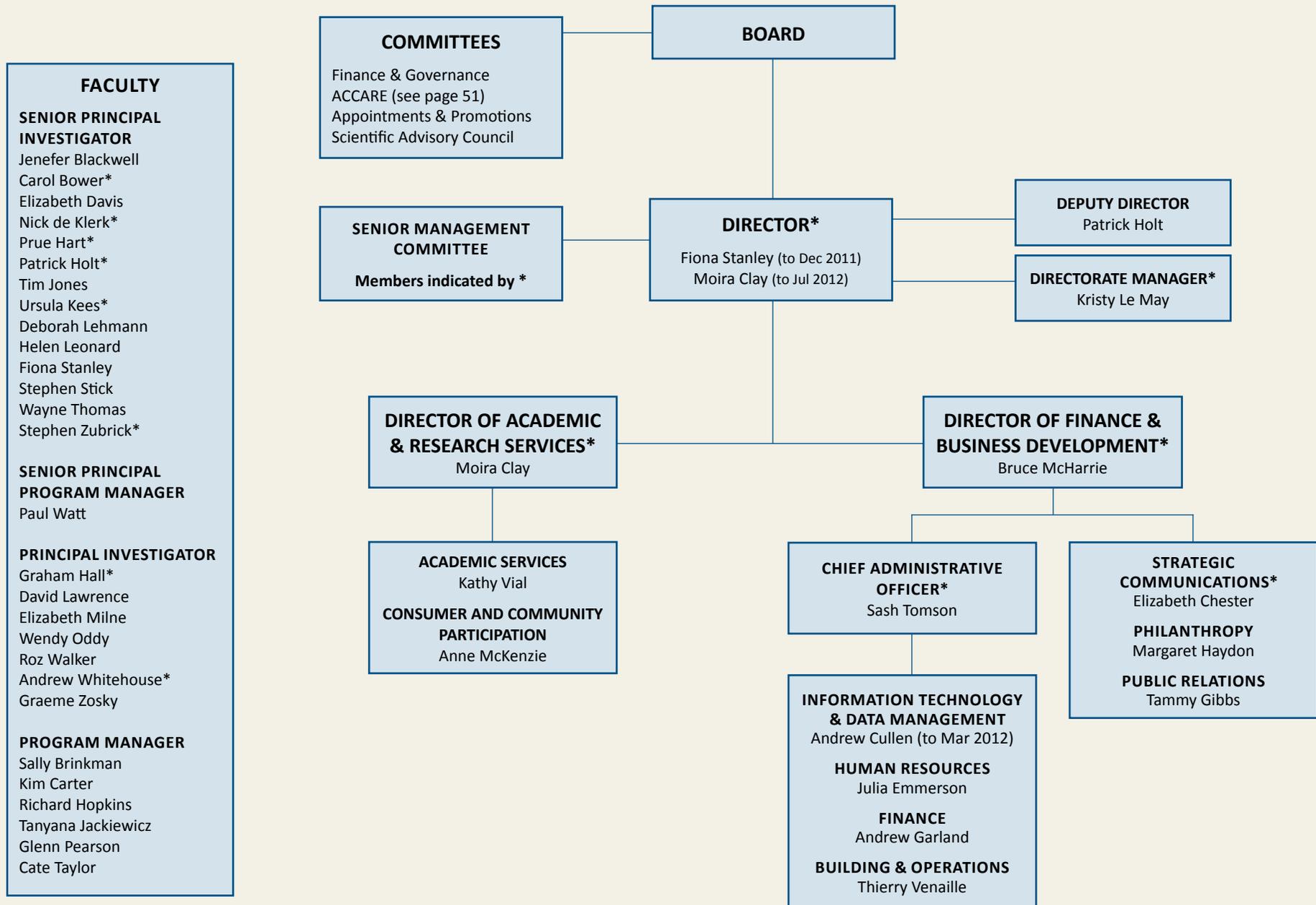
Total staff and students in 2011 - 445

Total number of honorary and visiting scientists during the year - 143

# RESEARCH INCOME

<b>AUSTRALIAN COMPETITIVE GRANTS</b>			<b>COMMERCIAL INCOME</b>		
Australian Research Council	229,440		Advanced Diagnostic Systems Pty Ltd	40,742	
Australian Rotary Health Research Fund	56,250		AiMedics Pty Ltd	303,698	
Cystic Fibrosis Association	45,953		Apache Energy Limited	100,000	
National Health and Medical Research Council	6,888,315		Baxter Healthcare Pty Ltd	35,000	
National Heart Foundation Australia	71,220		BHP Billiton Australia Limited	182,762	
	<b>7,291,178</b>		GlaxoSmithKline Australia Pty Ltd	89,465	
<b>INTERNATIONAL COMPETITIVE GRANTS</b>			GlaxoSmithKline Biologicals SA	3,955	
Autism Speaks Inc	57,161		Hawaiian Investments Pty Ltd	44,044	
British Heart Foundation	5,675		Ipsen Pty Ltd	10,000	
Cystic Fibrosis Foundation Therapeutics	317,152		Johnson & Johnson Pharmaceutical Research & Development	65,107	
International Rett Syndrome Association	63,349		Kendle R&D Pty Ltd	169,282	
Juvenile Diabetes Research Foundation International	299,863		MedImmune Inc	87,000	
Miscellaneous Overseas Grants	1,010		Merck Sharpe & Dohme (Australia) Pty Ltd	9,858	
National Institutes of Health	701,699		Novartis Vaccines and Diagnostics Pty Ltd	124,457	
	<b>1,445,909</b>		Novo Nordisk Pharmaceuticals Pty Ltd	80,000	
<b>OTHER COMPETITIVE GRANTS</b>			Pfizer Pty Ltd	277,616	
Asthma Foundation of Western Australia	27,662		Phylogica Limited	2,681,674	
Brightspark Foundation	187,316		PPD Australia Pty Ltd	24,516	
Cancer Foundation of Western Australia	240,232		Sanofi Aventis Australia Pty Ltd	138,912	
Children's Leukaemia and Cancer Research Foundation	632,601		Wyeth Australia Pty Ltd	39,020	
Foundation for Alcohol Research and Education	2,860				
Foundation for Children	67,749				<b>4,507,108</b>
Healthway	48,821		<b>OTHER GRANTS</b>		
Melbourne Health	22,031		Australian & New Zealand Society of Respiratory Science	13,636	
Raine Foundation	75,000		Australian Paediatric Surveillance Unit	27,656	
Lotterywest	20,000		Children's Cancer Institute Australia for Medical Research	15,000	
	<b>1,324,272</b>		Confederation of Meningitis Organisations (CoMO)	122,905	
<b>GOVERNMENT CONTRACTS</b>			Curtin University	94,941	
Western Australia			Edith Cowan University	3,000	
Department of Child Protection	50,743		Friends of the Institute for Child Health Research	18,089	
Department of Commerce	200,000		Ian Potter Foundation	3,000	
Department of Education	1,160		King Edward Memorial Hospital	5,000	
Department of Health	1,914,791		Juvenile Diabetes Research Foundation	1,619	
Department of Indigenous Affairs	3,000		Miscellaneous	6,499	
Disability Services Commission	56,315		Papua New Guinea Institute of Medical Research	50,130	
Office of Science and Innovation	231,830		Princess Margaret Hospital	392,833	
Federal			Princess Margaret Hospital Foundation	40,000	
Australian Agency for International Development	199,100		Royal Perth Hospital	26,000	
Australian Organ and Tissue Donation and Transplantation Authority	23,335		The Royal Children's Hospital	231,059	
Department of Education, Employment and Workplace Relations	199,318		Thoracic Society of Australia & New Zealand	15,000	
Department of Families, Housing, Community Services and Indigenous Affairs	179		University of Cambridge	17,896	
Department of Health and Ageing	1,029,573		University of Queensland	139,884	
Department of Innovation, Industry, Science and Research	940,788		University of Sydney	20,182	
Other			University of Western Australia	2,977,043	
Department of Education and Children's Services, South Australia	26,214			<b>4,221,372</b>	
Miscellaneous - Non-WA State Governments	28,688		Miscellaneous income	322,871	
	<b>4,905,034</b>			<b>24,017,744</b>	
			<b>TOTAL</b>		

# MANAGEMENT/OPERATING STRUCTURE





*Delivering hope through  
life-changing research*

For further information about donating to the Institute, including the Institute in your Will or other gifting opportunities, please contact us on:

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email - [pr@ichr.uwa.edu.au](mailto:pr@ichr.uwa.edu.au)

website - [www.childhealthresearch.org.au](http://www.childhealthresearch.org.au)



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