



Telethon Institute for  
Child Health  
Research

OUR DIRECTOR PROFESSOR JONATHAN CARAPETIS  
WITH BABY REMY

working together  
ANNUAL REPORT 2012

The Telethon Institute for Child Health Research is affiliated with The University of Western Australia through the Centre for Child Health Research and has strong clinical research links to Princess Margaret Hospital for Children.



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WESTERN AUSTRALIA**

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**Government of Western Australia**  
Department of Health  
Child and Adolescent Health Service



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Telethon Institute for  
**Child Health Research**

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# working together

*Coming together is a beginning, staying together is progress, and working together is success.*

- Henry Ford

Long gone are the days where research was conducted in isolation – where an individual scientist would make a startling discovery staring down a microscope or at statistics.

Today's scientific endeavours are bigger in scope and scale, driven by huge amounts of data that have been unleashed by the mapping of the human genome and our ability to delve deeper into the biological, social and environmental factors that affect health and wellbeing.

It's complex work to tackle complex problems, and requires a multi-pronged approach.

That's why today's best research organisations are working together, harnessing the power of their collective activities.

But that's not enough.

For more information go to [childhealthresearch.org.au](http://childhealthresearch.org.au)

What about the clinicians, the families, the policy makers and the communities who might have different questions and insights?

The new strategic plan of the Telethon Institute for Child Health Research recognises the importance of all these partnerships.

Working together we see a much more detailed picture than we can working apart.

The result?

Research that is more relevant and responsive to community and clinical needs.

Research that results in knowledge being shared and valued.

This report features just some of our collaborations.



# STRATEGIC PLAN 2013-2017

The Telethon Institute is entering an exciting stage of development, guided by a new strategic plan to achieve our vision **to improve the health and wellbeing of children through excellence in research.**

Our goal over the next five years is to create a new blueprint for a research institute – one that embraces its community and judges itself by its ability to make a difference in that community.

You can download a copy of our plan at [childhealthresearch.org.au](http://childhealthresearch.org.au)

## VALUES

- **WE MAKE A DIFFERENCE** by ensuring our research is translated into action now and in the future.
- **WE CHALLENGE** existing ideas and ourselves, and seek innovative and creative ways of working.
- **WE WORK TOGETHER** and with our community to bring better health and wellbeing to children.
- **WE CARE** for children and the community, in Western Australia and beyond.
- **WE RESPECT** the contributions of all who work at and with the Institute.
- **WE UPHOLD** these values as a measure of our success and the integrity of our work and organisation.

## STRATEGIC GOALS

- 1** Our research will be driven by its potential to improve health and wellbeing of children
- 2** We will work together with stakeholders to achieve the best health and wellbeing outcomes for children
- 3** We will build capacity and excellence in our people, in recognition that they are our greatest asset
- 4** We will be a great organisation in the eyes of our staff, supporters and other stakeholders
- 5** We will diversify and increase our funding base to sustain our activities and future growth



# NEW BUILDING PROJECT

Construction has begun of the Telethon Institute's cutting-edge facility within the new children's hospital project in Nedlands.

The State Government is generously funding the Institute's new home as part of a visionary plan for a world-class integrated research, education and clinical facility to enhance the relationship between child health research and clinical care. The Australian Government is also a key supporter of this project with a \$40 million commitment to the fitout of the Institute building.

The move into the new Institute in early 2016 will mean a significant increase in useable space as well as better connectivity with other child health researchers and clinicians.

Architectural firm Woods Bagot has been engaged to assist the Telethon Institute in refining its design brief as it works with the new children's hospital team to create an exciting new workplace with state-of-the-art laboratory facilities.





## 2012 HIGHLIGHTS

The Telethon Institute continues to conduct high quality research to improve the health and wellbeing of all children. In 2012, our researchers were nationally and internationally recognised for their unwavering commitment to multidisciplinary research, their forward-thinking research programs, and their ongoing advocacy for the health and wellbeing of children. The year also saw the Telethon Institute partner with numerous international research leaders and institutions on pioneering research initiatives.

### EXCELLENCE IN RESEARCH LEADERSHIP

In the Queen's Birthday Honours List, Associate Professor Deborah Lehmann, who heads our infectious diseases research program, was recognised with the award of Officer in the Order of Australia (AO).

Professor Moira Clay, our Director of Academic and Research Services was announced as the new President of the Australasian Research Management Society (ARMS).

A program of research to uncover the key drivers to improve child health and wellbeing, led by Western Australia's most experienced and respected health researchers including Professors Fiona Stanley, Steve Zubrick, Carol Bower, Nick de Klerk, Sven Silburn, Associate Professor Deborah Lehmann and Dr Helen Leonard, was recognised as one of the Ten of the Best Research Projects of 2011 by the National Health and Medical Research Council.

Our researchers were awarded \$3.46 million in competitive project grants and two early career fellowships (to Monique Robinson and Gavin Pereira) from the Federal Government's National Health and Medical Research Council. The funding will enable them to lead seven new research projects, focussed around respiratory health and diabetes.

Dr Lea-Ann Kirkham was awarded a Young Tall Poppy Science Award for her vaccine research.

Professors Fiona Stanley and Steve Zubrick were appointed as inaugural Ambassadors for Children and Young People by the Commissioner for Children and Young People Michelle Scott

### EXCELLENCE IN RESEARCH TEACHING

We continue to be a world-class teacher of the next generation of health researchers. In 2012, our management team created a highly successful and forward-thinking Research Leadership Program aimed at developing future research leaders. The Australasian Research Management Society recognised this program with a national award for excellence

TEN OF THE BEST: DEBORAH LEHMANN, CAROL BOWER, NICK DE KLERK, FIONA STANLEY, STEVE ZUBRICK AND HELEN LEONARD



in the category of 'Research Management Innovation'. The program was developed in collaboration the University of Western Australia.

During 2012, we supported 96 Honours, Masters and PhD students with seven of our students successfully completing their PhD degrees and graduating.

Our researchers contributed to 253 publications including journal articles, book chapters, peer-reviewed conference papers and reports.



ASSOCIATE PROFESSOR DEBORAH LEHMANN WITH RILEY

## EXCELLENCE IN RESEARCH COLLABORATION

### Bioinformatics

The nature of scientific research has changed dramatically over the last two decades. Major factors driving change have been the completion of the Human Genome Project and the computing and internet revolutions.

Modern science means a single experiment can generate millions of results, which need to be analysed alongside the wealth of existing data. Today, the majority of scientific research projects cannot succeed without the intervention of advanced computing. With an ever increasing reliance on the computational analysis of research data, a new research field has arisen to fill the void - Bioinformatics.

Our Institute stands at the forefront of this new research frontier with a \$1.3 million funding boost to launch The McCusker Charitable Foundation Bioinformatics Centre. The Bioinformatics Centre will significantly accelerate research into child health diseases

and disorders and will ensure the Institute continues to set the pace in this field. The funding will support the employment of three bioinformaticians, two PhD scholarships and two honours scholarships in this emerging field.

### Fraser Mustard Centre

Australian children will benefit from a research partnership between the Institute and the South Australian Department for Education and Child Development to create The Fraser Mustard Centre. The aim of this innovative partnership is to improve the developmental, health and educational outcomes for children and young people by bringing together leading Australian child researchers, government policy makers and planners.

### LOOKING at Language

The largest, longest and most comprehensive study of language and literacy development in the world continues after being awarded a prestigious international grant. The Looking at Language study has been extended for a further five years following the third

successive renewal of its funding from the USA based National Institutes of Health. The project, which began in 2002, is an international collaboration between the University of Western Australia affiliated Telethon Institute, Kansas University and the University of Nebraska Medical Center.

### Data Linkage

In May 2012, we co-hosted the International Data Linkage Conference, a major international conference celebrating the role of data linkage in improving health and social outcomes. More than 300 guests from as far afield as Canada, the UK, USA, Scandanavia and across Australia descended on Perth for the conference which was co-hosted by The University of Western Australia, Curtin University and the WA Department of Health.

## EXCELLENCE IN RESEARCH DISCOVERIES

### Folate before pregnancy protects against childhood brain tumours

A national study led by our researchers has found folic acid supplements taken before and during pregnancy reduces the risk of childhood brain tumours.

Study leader Professor Elizabeth Milne said while other studies had investigated the impact of multivitamin supplements, this research project was the first to separate out different types of supplements, including folic acid and other B group vitamins.

HIS EXCELLENCY THE GOVERNOR OF WESTERN AUSTRALIA MR MALCOLM McCUSKER WITH MRS TONYA McCUSKER, THEIR DAUGHTER MARY, AND INSTITUTE BIOINFORMATICIANS DR KIM CARTER AND RICHARD FRANCIS



### Vitamin B crucial to children's mental health

A new study has uncovered a significant link between vitamin B levels and the mental health and wellbeing of children and adolescents.

Researcher Carly Herbison said the study is the first to report on a direct link between the prevalence of externalising behaviour problems in adolescents at 17 years and a reduced intake of B1, B2, B5, B6 and folate.

The study reinforces how a healthy diet can play a key role in improving mental health outcomes for young people.





### New insights into genetics of aggressive cancer

Researchers have found new genetic differences in one of the rarest and most aggressive types of children's cancer that may present new opportunities in treating the disease, NUT-midline carcinoma (NMC).

There are very few established cell-lines of NMC for research in the world. Three of these have been grown by our research team. The next step is to test a range of existing drugs against this particular genetic target. At the moment, clinicians have no effective treatments for NMC and it's crucial that we find therapies that can slow or stop this terrible disease.

### Life at 7

We've laughed and cried as film crews have followed the growth and development of a special group of Aussie kids living in ordinary and extraordinary circumstances.

In 2012, the kids turned seven and the Life Series gave us an insight into their temperaments and personalities as they progress through school.

The Institute's Professor Steve Zubrick has provided expert commentary throughout the documentaries which have been made in conjunction with a long-term study - The Longitudinal Study of Australian Children ('Growing Up in Australia') - in which 10,000 children have been placed under a sociological and scientific microscope.



BEN, ONE OF THE LIFE AT 7 KIDS

### Arsenic in drinking water linked to lung disease

New research has uncovered likely mechanisms for the link between arsenic in drinking water and increased risk of developing chronic lung disease.

Lead author Kathryn Ramsey said the research team used animal models to determine that even low levels of arsenic exposure in the womb alone could cause serious problems in lung development which may increase the risk of chronic respiratory infections in childhood.

The next step in our research is to try and identify at what concentration arsenic causes detectable changes in lung growth so we can better inform public health policies around water quality.

### Study links testosterone levels in the womb and language problems

Boys who are exposed to high levels of testosterone before birth are twice as likely to experience delays in language development. The study, led by Winthrop Professor Andrew Whitehouse, used umbilical cord blood to explore the presence of testosterone when the language-related regions of a fetus' brain are undergoing a critical period of growth.

Dr Whitehouse said the finding is significant in that it gives a biological explanation for why boys' language development differs to that in girls.

### Study brings good news for assisted pregnancy

A new study has uncovered a significant decline in the risk of birth defects amongst WA children born using Assisted Reproductive Technology (ART). The study showed the risk of birth defects amongst single babies born using ART in WA dropped from 10.9 per cent between 1994 and 1998 to 7.5 per cent in the four years following (1998-2002), compared with a rate of 5.2 per cent in the naturally conceived group.

Changes to clinical practice may be largely responsible with improved culture media and better culture and storage conditions leading to the transfer of 'healthier' embryos. The research team hope to continue monitoring birth defects to evaluate the impact of more recent changes to ART laboratory practice such as extended blastocyst culture and vitrification (rapid freezing of eggs and embryos).

KATE HAFEKOST



### Too many sugary drinks for Aussie kids

The consumption of sugary drinks is high amongst Australian children and adolescents with the majority consumed in the home. Researcher Kate Hafekost said around 80 per cent of Australian children drank sugary drinks which include carbonated soft drinks (including energy drinks), juices with added sugar, cordial, sports drinks, milkshakes/smoothies and flavoured milk.

The study found the majority (77 per cent) of sugary drinks were purchased in supermarkets and 60 per cent were consumed in the home environment. As such, the study team believes parents and children need to be educated about the consequences of high consumption of both carbonated and non-carbonated sugary drinks as they contribute to obesity as well as nutrition-related chronic disease.



### Celebrating 20 years of meningitis awareness

Institute-based charity The Meningitis Centre celebrated a milestone 20th year of providing meningitis awareness and support to Australian families. Established on 24 April 1992, the organisation was founded by a group of parents and health care professionals who recognised the need to raise public awareness of meningitis.

Over two decades, The Meningitis Centre has played an integral role in lobbying for vaccines to prevent strains of meningitis, and was involved in getting the pneumococcal vaccine on the National Immunisation Program.

### Research provides new insights into the cause of asthma attacks

Dr Anthony Bosco has been recognised for his cutting-edge research investigating asthma attacks in children, honoured with an 'Early Career Award' from the University of Western Australia for the most outstanding published work accepted in 2010-11.

Dr Bosco, in collaboration with Professor Fernando Martinez from the University of Arizona, has discovered a network of inflammatory genes that cause asthma attacks in children. The results could pave the way for the development of new drugs to combat this chronic lung disease which affects more than two million Australians.

### New vaccine shows promise in protecting against common cause of meningitis

Researchers are an important step closer to finding a vaccine that protects against a wide range of strains of meningococcal B - the most common cause of meningitis in WA.



Associate Professor Peter Richmond, Head of our Vaccine Trials Group, said the trial data showed the potential vaccine produced protective antibodies against 90 per cent of the invasive meningococcus serogroup B strains tested. The next stage of development would involve bigger trials in a wider range of age groups.

### Researchers lead mental health survey of Australia's children

Our researchers will lead a comprehensive national survey of the mental health of Australia's children. The 2nd Child and Adolescent Component of the National Survey of Mental Health and Wellbeing will take place between May and September 2013, gathering information about the mental health status of approximately 5000 children aged between four and 17 years from across Australia.

Funded by the Australian Government Department of Health and Ageing, the \$6 million study is the first national survey of its type in 15 years and will be headed by Professors Stephen Zubrick and David Lawrence.

### Exposure to diesel exhaust increases risk of child brain tumours

A correlation between brain tumours in young children and their parents' exposure to diesel exhaust fumes before the birth has been described in a study by Institute researchers.

MENINGITIS SURVIVORS ASHLEIGH LANGOULANT AND WEST COAST EAGLE ADAM SELWOOD

The study found that fathers who worked near diesel powered equipment including cars, trucks, other heavy machinery and generators at about the time of conception, had children with an increased risk of child brain tumours. There was also an increased risk for mothers exposed to diesel exhaust any time before the child's birth.

### Research links poor language to lack of vitamin D in womb

Children of mums who had low levels of vitamin D during pregnancy are twice as likely to have language difficulties. The study, the largest of its kind, looked at vitamin D concentrations during the pregnancies of more than 740 women, with follow-up investigations of their child's development and behaviour at regular periods up to 17 years of age.

Lead author, Winthrop Professor Andrew Whitehouse, said the finding was significant given that vitamin D levels among women are known to have decreased steadily over the past 20 years.

### Global Symposium on Childhood Brain Tumours

Throughout 2012, The Telethon Adventurers raised funds for a Global Symposium on Childhood Brain Tumours. In February 2013, 50 of the world's top childhood brain tumour experts arrived in WA for the Symposium hosted by the Telethon Institute.

Neurosurgeons, oncologists and researchers from the USA, Canada, United Kingdom, Europe, New Zealand and Australia came together to share the latest research, data and treatment options for the invasive brain tumour medulloblastoma, which aggressively targets young children, primarily under the age of five.

By bringing together the world's best childhood brain tumour experts, the Telethon Adventurers hope to find a cure and ways to decrease the devastating long-term side effects of treatment by synchronising international research and converting discoveries into new treatments.

It was a truly ground-breaking three days and the Symposium ended with a promise to develop a joint battle plan against medulloblastoma.



## CHAIRMAN'S REPORT

It is often said that change brings opportunity and that has certainly been the experience for the Telethon Institute over the past year.

The key trigger of course was the retirement of the founding Director, Professor Fiona Stanley. To farewell a leader of her calibre and reputation forces an organisation to take a very serious look at its future direction, particularly as we considered the leadership that would be needed to inspire and guide a new-look Institute.

It was therefore with great expectation that we welcomed Professor Jonathan Carapetis in July as the new Director of the Telethon Institute for Child Health Research.

Jonathan's appointment followed an extensive recruitment exercise, generously undertaken by Gerard Daniels on a pro bono basis, to identify international leaders in child health research. While there were a number of excellent candidates nationally and from Europe and North America, there was no-one with better expertise or vision.

In Jonathan's most recent leadership position as Director of the Menzies School of Health Research in Darwin, the organisation doubled in size, tripled research income, and developed a reputation for high-quality, translational research. As a paediatrician and infectious disease specialist, he has demonstrated a passion to improve Aboriginal child health and is recognised as the world expert in research to prevent and treat rheumatic heart disease.

The Board's expectations were reinforced as Jonathan immediately launched into a

comprehensive process with us to develop a strategic plan to guide the Institute's direction over the next five years.

He has challenged the model for how research institutes are structured and measured, and questioned at every stage how the Institute's research will be relevant and responsive to community needs and lead to tangible improvements to child health and wellbeing.

The result is a bold and ambitious plan with a strong focus on collaboration. It is not something the Institute can achieve alone, but will require even more effective partnerships with policy makers, clinicians, the community and funders.

Indeed the support we received for the Fiona Stanley Tribute lunch, hosted by Channel 7's Telethon and The West Australian, will help us to attract and retain the next generation of research leaders that will implement this plan. Our thanks go to those generous donors, led by Mr Jack Bendat, Wesfarmers and Apache, and the many other supporters of this event. In her role now as Patron, Professor Fiona Stanley remains an inspiration and mentor as the Institute's vision continues to grow.

The election pledge by the Western Australian State Government to invest a further \$30 million into health and medical research along with Premier Colin Barnett's personal stewardship of the Science portfolio reflects the growing significance of this sector to the State.

I'd like to take this opportunity to thank my fellow Directors for their commitment and support over the past year. In particular, we

acknowledge and farewell Professor Margaret Seares after two years of outstanding service to the Board, and Professor Rhonda Marriott who I am pleased to say has taken up a research position at the Institute.

We were very fortunate to secure the services of University of Western Australia Deputy Vice-Chancellor (Research) Professor Robyn Owens and Mr Michael McAnearney, the Chief Executive of Gerard Daniels. They both bring exceptional expertise as we work together to implement the Institute's strategic plan.

I congratulate the executive leadership group of Jonathan Carapetis, Moira Clay and Bruce McHarrie for their steady steerage of the Institute through a year of such significant change, while at the same time identifying so many new opportunities.

Finally, I acknowledge the researchers, professional support staff and students who continue to work together to achieve the vision of improving child health and wellbeing. We never forget that you are the core and the heart of this organisation and the key to its ongoing success.

**John Langoulant AO  
Chair**





# BOARD OF DIRECTORS

Our Board of Directors all give their time voluntarily and work together to guide the overall business of the Institute, bringing a diverse range of experience from the business, academic and community sectors. We are extremely grateful for their dedication and the governance they provide us.



**JOHN LANGOULANT AO (CHAIR)**

Chief Executive, Oakajee Port and Rail and Crosslands Resources Pty Ltd; Chair, Government Employees' Superannuation Board; Chair, Leadership WA; Chair, Western Australian Ballet; Chair, Committee for Perth; Chair, Dampier to Bunbury Pipeline; Board Member, Council of Australian Governments' Reform Council; Chair, Bankwest Curtin Economic Centre Advisory Board; Board Member, Chamber of Commerce and Industry WA.



**JONATHAN CARAPETIS**

Director, Telethon Institute for Child Health Research (from 23 Jul 2012); Member, State Health Research Advisory Council; Former Chair, Advisory Board for Centre for School Leadership, Learning and Development, Charles Darwin University; Member, One Disease at a Time Board; Member, Program Management Committee, RHD Australia; Member, National Committee for Medicine, Australian Academy of Science; Chair, Clinical Advisory Group, WA RHD Control Programme.



**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; Chairman, Sirius Resources NL; Chairman, St Andrews Insurance Ltd; Deputy Chair, Metropolitan Redevelopment Authority.



**ANNE KELSO AO**

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



**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.



**MICHAEL McANEARNEY**

Director and CEO International, Gerard Daniels Australia; Member, Australian Institute of Company Directors; Director, Duke of Edinburgh Award WA.



**JIM MCGINTY**

Chairman, Health Workforce Australia; Board Member, Australian Medicare Local Alliance; Former WA State Health Minister; Former WA Attorney General.



**ROBYN OWENS**

Deputy Vice-Chancellor (Research), The University of Western Australia; Member, Australian Astronomical Observatory Advisory Committee; Member, Centre for Ethical Leadership Advisory Board; Member, International Centre for Radio Astronomy Research Board; Member, National eResearch Collaboration Tool & Resources Project; Alternate Member, Western Australian Institute of Medical Research; Member, Astronomy Australia Limited.

## Retired from the Board during 2012:

Moira Clay, Rhonda Marriott, Margaret Seares





# DIRECTOR'S REPORT

For me, there has always been one overriding objective of research: to improve child health and wellbeing. The corollary is that we should judge the success of our research by how it contributes to this objective.

Academic measures such as publication in a highly-respected journal are of course very important, but should not be the end of the story.

Indeed, the Telethon Institute's reputation for action and advocacy was a strong factor in my decision to accept the role as Director.

I am very pleased to report that this commitment to translating research into actions that will improve lives, particularly in policy and clinical practice, is now entrenched in the Institute's new strategic plan, unveiled in April.

So what does that mean in reality? It means that the Institute has committed to working much more closely with the community, policy makers and service providers to ensure the research we do is answering the most important questions, not just with a view to creating new knowledge, but with a practical perspective on how that knowledge could be used.

It doesn't mean that we won't continue to do the intricate basic laboratory science that is so important in unlocking the mechanisms of disease. This is an absolutely critical aspect of our work. But we will make sure we always ask, where does this lead next?

This approach requires the Institute to be more outwardly focussed, working together with stakeholders to achieve the best outcomes for children. It's a challenge that has been greeted with great enthusiasm from outside the Institute and within.

It is also the philosophy that underpins the Institute's move to within the new children's hospital building on the campus of the Queen Elizabeth II Medical Centre in Nedlands in 2016.

In providing generous funding for the project, the State Government's intention is to create a world-class facility for child and adolescent clinical care and research.

We are working with our designers to push the limits in creating dynamic, collaborative spaces to bring together laboratory scientists, population researchers and clinicians and literally open up the Institute.

There's no doubt that West Australians are very committed to improving child health here and beyond. That became very evident to me during my first experience with Channel 7's Telethon in November.

While I had heard much about the "Telethon spirit," it was humbling and invigorating to see it in action. The community feeling for the importance of our work was palpable. Not only does Telethon significantly support the costs of our research, it is a powerful connection for us to the community and inspires us to deliver our vision.

Being appointed as Director of the Telethon Institute for Child Health Research comes with great challenge and opportunity.

I am very fortunate to have received enormous support from the Board, and in particular our Chairman, Mr John Langoulant. Board members have been generous with their insight and experience.

I'd also like to thank Institute Directors Professor

Moira Clay and Mr Bruce McHarrie for their warm welcome, advice and commitment to ensuring the smooth running of the organisation.

Finally, I'd like to thank the Institute's staff and students and all our supporters for their contribution to the development of our new strategic plan and their enthusiasm for the exciting years ahead.



**Jonathan Carapetis**  
Director



# OUR SUPPORTERS

The altruistic support the Institute receives from community-minded donors greatly contributes to our aim of improving the health and wellbeing of children. Our passionate donors not only give practical support but inspire our researchers and support staff 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 our 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.

Telethon 2012 was an extraordinary success raising a record \$16,805,622 which is distributed to 44 beneficiaries working to benefit children including, of course, the Telethon Institute. Beating last year's record of \$13.4m, this took the total raised since 1968 to \$133 million.

A highlight event for both Telethon and the Telethon Institute was the Fiona Stanley Tribute held in May 2012 which raised \$580,000 for Telethon. Major donors for the Tribute included Jack Bendat, pictured below at the Tribute lunch with Channel 7's Basil Zempilas and the Premier of Western Australia Colin Barnett.

Thanks Telethon and thanks Western Australia for your ongoing support.



PHOTOS COURTESY THE WEST AUSTRALIAN





## THE TELETHON ADVENTURERS RAISE \$1.8 MILLION

The Telethon Adventurers built on their extraordinary fundraising success in the past two years raising a record \$1.8 million in 2012.



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, including 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 cancer.

Woolworths joined the Telethon Adventurers, holding a bike ride from Esperance to Perth and a

fundraising promotion in all WA stores.

Telethon Adventurers co-founder, Peter Wilson, led the Woolworths Ride for Elliot in November 2012. The 12 riders covered 2,100 km in 14 days, battling rain, winds and fatigue as they circled Australia's South West. The ride crossed the finish line at the Perth Convention and Exhibition Centre on Telethon weekend where they announced they raised over \$500,000.

The Telethon Adventurers also saw one of their early visions become a reality when the Institute hosted the Global Symposium on Childhood Brain Tumours. Fifty of the world's top childhood brain tumour experts arrived in WA to share the latest research, data and treatment options for the invasive brain tumour medulloblastoma.

ABOVE LEFT: TELETHON ADVENTURERS HELPING EACH OTHER TOWARDS THE FINISH LINE ON THE 2,100 KM RIDE

## CHILDREN'S LEUKAEMIA AND CANCER RESEARCH FOUNDATION UNDERPINS INSTITUTE'S CANCER RESEARCH

Since the establishment of the Telethon Institute, the Children's Leukaemia and Cancer Research 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.

One of those researchers is Dr Alex Beesley, who received the Children's Leukaemia and Cancer Research Foundation Fellowship.

Alex obtained his PhD in 1996 from Sheffield University in the UK and then completed two postdoctoral research positions at Sheffield University and then at Sydney University. He joined the Division of Leukaemia and Cancer Research at the Telethon Institute in 2003 to study the mechanisms of relapse and resistance in childhood cancer alongside Professor Ursula Kees. Initially focusing on paediatric leukaemia, this work has now expanded to include other rare forms of cancer affecting children and Alex is also responsible for the co-direction of leukaemia research, staff and students within the laboratory.

Thanks to the Foundation and their supporters including their major supporter, Woolworths.

ABOVE RIGHT: ALEX BEESLEY WITH PHIL BRUCE, VICE CHAIRMAN OF THE FOUNDATION



## McCUSKER CHARITABLE FOUNDATION FUNDS CUTTING-EDGE TECHNOLOGY

The three-year funding from the McCusker Charitable Foundation has enabled the establishment of a Centre of Bioinformatics which will significantly accelerate research into childhood diseases and disorders. The launch of the new Centre means that Western Australia not only keeps up, but can help set the pace in this rapidly developing field of science.

HIS EXCELLENCY AND MRS McCUSKER AT THE LAUNCH OF THE BIOINFORMATICS CENTRE WITH THE INSTITUTE'S RICHARD FRANCIS

## BRIGHT BLUE RIDE FOR RESEARCH

Throughout 2012, the Police Commissioner's Fund for Sick Kids, "Bright Blue", continued fundraising towards their goal of funding a Cancer Analysis Suite at the Telethon Institute.

In June, 44 riders and supporters gathered in Derby for the Gibb River Ride. The extraordinary thing about the 740km ride from Derby to Kununurra was that the police officers undertook the ride on standard ex-Australia Post bikes. The "postie" bikes were donated by Australia Post and initially the very small bikes were a challenge for the police who were used to riding something much sturdier.

The Telethon Institute is extremely grateful to Commission O'Callaghan and the members of the WA Police for their commitment to improving the lives of sick kids.



POLICE COMMISSIONER KARL O'CALLAGHAN WITH TELETHON INSTITUTE RESEARCHER DR PETER DALLAS INSPECTING THE "POSTIE" BIKES, DONATED BY AUSTRALIA POST

## ALLEGRA SCAFIDAS FUND

When six-month-old Allegra Scafidas died from pneumococcal meningitis in 2010, her parents Elias Scafidas and Nhon Vo decided to establish the Allegra Scafidas Fund in partnership with the Telethon Institute to ensure that no other child will miss out on life-saving vaccines. The Fund was established in 2011 with a gift of \$250,000 and officially launched in 2012. The aim is to build the fund and further develop the pneumococcal laboratory established in Allegra's name to target more than 90 strains of the bacterial family that killed their daughter.



DR PETER RICHMOND, HEAD OF THE INSTITUTE'S VACCINE TRIALS RESEARCH GROUP, WITH ALLEGRA'S PARENTS, NHON VO AND ELIAS SCAFIDAS AT THE FUND LAUNCH



STAN AND JEAN PERRON WITH THE 2012 PERRON CHARITABLE FOUNDATION SCHOLARSHIP RECIPIENTS



ETHAN WITH HIS PARENTS CHRISTIE-LEE AND SHANNON DAVIES AT THE LAUNCH OF THE ETHAN DAVIES SCHOLARSHIP



## STAN PERRON CHARITABLE FOUNDATION

Through the Perron Charitable Foundation, Stan and Jean Perron have supported the Institute since its inception. Mr Perron 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 to support outstanding researchers.

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The Mitsubishi Development Pty Ltd Clinical Suite has been made possible with a generous donation by Mitsubishi Development. The Suite enables researchers to undertake clinical trials and is used daily by the generous members of the public who participate in the wide range of clinical trials aimed at improving child health.

BELOW: TELETHON INSTITUTE CHAIRMAN JOHN LANGOULANT AO, KEISUKE HOSHINO (MANAGING DIRECTOR & CEO, MITSUBISHI DEVELOPMENT), KAORU YAMANAKA (SENIOR VICE PRESIDENT, EXECUTIVE ASSISTANT TO THE METALS GROUP CEO) AND PROFESSOR FIONA STANLEY AC

## ETHAN DAVIES SCHOLARSHIP FUND

A new research scholarship to combat childhood brain tumours has been established in honour of Perth toddler Ethan Davies.

Ethan was diagnosed in January 2012 with ependymoma, a rare form of brain tumour, and has undergone complex surgery, chemotherapy and specialised radiation.

Ethan's parents Shannon and Christie-Lee have established the annual Ethan Davies Scholarship for Brain Cancer Research which will support a researcher in the Brain Tumour Laboratory with a specific interest in ependymoma. The annual fund raised over \$150,000 in its first year.

With the support of the Ethan Davies Scholarship, we hope to accelerate the development and introduction of new and improved treatments to prevent and better treat this devastating cause of illness in children.



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# FIONA STANLEY TRIBUTE

As Founding Director Professor Fiona Stanley retired, her concern was for the next generation.

In response, The West Australian and Channel 7 Telethon launched the Fiona Stanley Tribute campaign to raise funds for the Institute to identify, develop and attract the next generation of child health research leaders. The generous contributions from business and the community has enabled the Institute to support the recruitment of two outstanding researchers who can now proudly wear the title of Fiona Stanley Investigators.

Our thanks to Mr Jack Bendat, Wesfarmers and Apache and all the donors for their support of these outstanding researchers.

## JASON NOW CALLS PERTH HOME

The wilderness of Australia's top end and the countryside of America's Pacific Northwest are a far cry from a research lab at the Telethon Institute, but for Dr Jason Waithman, the metropolis of Perth is where he needs to be.

"Exploring the natural environment of the Northern Territory and California as a kid with my brothers definitely kindled my inquisitive nature and my interest in natural biology and microsciences," says Jason.

These interests led Jason to complete a degree in microbiology and chemistry at Oregon State University in the USA and gain valuable work experience at various research institutes and organisations in Australia and the UK. It was during a period as a Research Assistant in the laboratory of Professor Ken Shortman at the Walter and Eliza Hall Institute in Melbourne that inspired Jason's long-term interest in a specific group of immune cells, dendritic cells.

"My interest in dendritic cells and knowledge of immunology allows me to now apply my expertise to cancer, in particular melanoma, an area where I feel my skills are needed," Jason said.

Jason moved to Perth in 2012 to further his research into tumour immunology at the cutting-edge facilities and complementary research programs offered at the Telethon Institute.

"Being presented with the Fiona Stanley Investigator Award, which

provides funding to initiate my laboratory and recruit a team of dynamic and talented researchers to examine immunity to melanoma, was instrumental in my decision to relocate my family to Perth," Jason said.

Jason and his team of researchers are investigating how the immune system interacts with melanoma and how it may be manipulated to destroy the melanoma.

"Melanoma is a devastating disease and we are exploring new ways to harness one's own immune cells to destroy the cancer," Jason said.

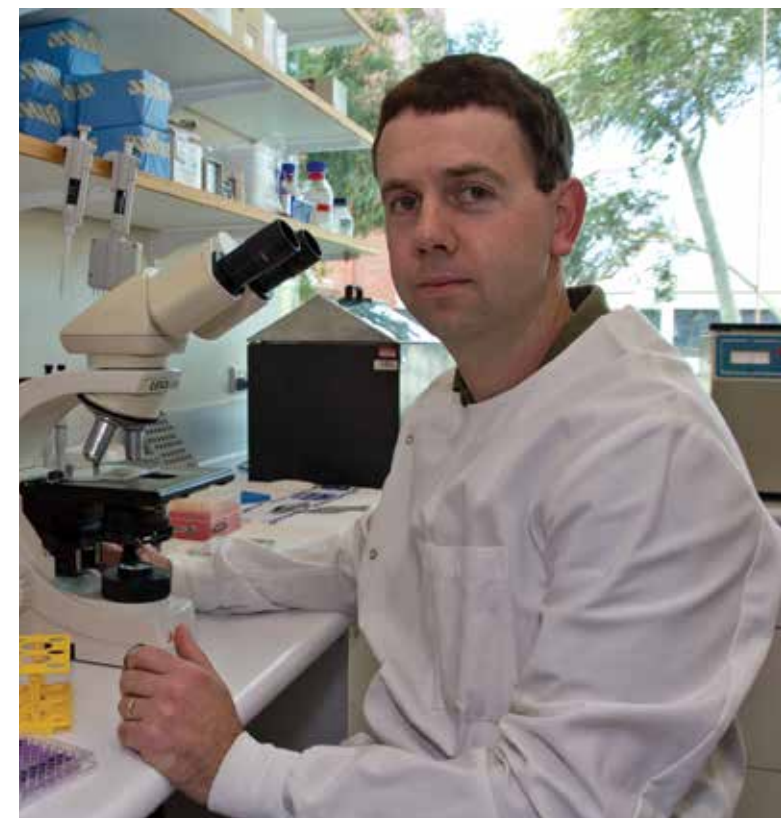
"This is achieved by understanding the interplay between various immune cells during melanoma and current therapies. This knowledge allows us to manipulate the immune cells providing better treatment and therapy options."

Frustrated at times by the slow pace of research, Jason remains hopeful about his role in cancer research.

"I enjoy the discovery side of research, finding out how things work, how to manipulate things. I'm hopeful that through collective and collaborative research over a long period of time we will assist in the treatment of melanoma," Jason said.

"I firmly believe that this generation of scientists will cure many forms of cancer and at the very least, prolong remission to extend quality of life."

When not finding a cure for melanoma, Jason enjoys playing soccer and spending quality time with his family.





## A DOCTOR ON A MISSION

Dr Tom Snelling is on a mission. The paediatrician, epidemiologist and vaccine safety advocate has already influenced opinion regarding how rotavirus vaccines should be used in Australia and overseas. Now, as he settles into his new role at the Telethon Institute, his next task is to direct his skills toward the nationwide assessment of the effectiveness and safety of Australia's broader vaccine programs.

Early in 2013, Tom marshalled his family and moved to Perth from Sydney, motivated by the opportunity to work in a dedicated paediatric research centre with close ties to a children's hospital.

"The move to Perth allows me to combine my clinical work as an Infectious Diseases Paediatrician at Princess Margaret Hospital with my work as an Honorary Postdoctoral Fellow at the Telethon Institute investigating vaccine effectiveness in children," says Tom.

Stirred by a deep interest in disease prevention, Tom looks at how vaccine strategies can be modified to ensure all children derive maximum benefit. His work to date has focussed largely on rotavirus and pertussis (whooping cough) vaccines and he wants to do all he can to ensure our children receive the best protection from our public health programs.

Whilst working in the Northern Territory, Tom discovered that despite its benefits, the existing rotavirus vaccine program was leaving many Aboriginal children still susceptible to the severe disease. This information was new and has since contributed to the understanding of how rotavirus vaccines work, influencing opinion on how they should be used in Australia and overseas. This work was first runner-up for the Public Health Association of Australia Aileen Plant Prize for the most outstanding Australian publication in infectious diseases epidemiology.

Tom is fast becoming recognised as an expert in methods to study vaccine impact and is building on this body of knowledge by collaborating on other projects including a nationwide evaluation of the pertussis and pneumococcal vaccine programs.

"The work we are doing on whooping cough is looking at how



effective the vaccine is in small children, and evaluating the effectiveness of so-called 'cocoon vaccination' of parents to protect babies while they are too young to receive vaccination," Tom said.

Tom expects this work will influence Australian and international policy regarding how pertussis vaccines are used. He believes the public expect and deserve to have their vaccination programs closely monitored by independent researchers so if a problem with safety or effectiveness emerges these issues are observed early and swift action can be taken.

Tom isn't scared to look deeply into the impact and safety of vaccines. A focus many researchers may steer away from.

"Unfortunately, scaremongering around vaccinations leads to concerns that even investigating vaccine safety and effectiveness might fuel the fire of public anxiety," Tom explains.

"However, the independent research conducted at the Telethon Institute is a positive step forward for the public as they can feel reassured that the vaccines our children receive are being independently monitored and their safety and effectiveness rigorously investigated."

The independent testing of the impact and effectiveness of vaccines does raise an extra hurdle for the researchers like Tom to overcome - funding. Investigator-led research is carried out by independent researchers who have no financial investment in the

outcomes of the study. Their interest is in ensuring the ongoing effectiveness of vaccines and confidence in the vaccine program, in Australia and overseas. As such, they rely on fundraising and competitive government grants to pay for the research and their salary.

"I'm grateful for the Fiona Stanley Investigator Award funding that allows me to continue my work at the Telethon Institute. I have benefitted greatly from the friendly environment, the encouragement to develop small scale projects, and the support to apply for competitive grants since I started here," Tom said.

The current round of funding will help Tom build on the existing body of vaccine-related infectious diseases research at the Telethon Institute as well as add to the clinical infectious diseases expertise at Princess Margaret Hospital.

As a father of two young children and paediatrician, Tom is acutely aware of concerns parents have around vaccinations.

"My hope is that the correct messages and accurate information about vaccines are put forward to parents. The field of vaccination is evolving. There still are, and always will be, important questions that need to be asked, investigated and the answers communicated effectively to parents," says Tom.

Tom's mission now - to ensure a sustainable program of vaccine monitoring is in place in Australia and overseas.

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

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





## WORKING TOGETHER: LOOKING AT LANGUAGE

PROFESSOR MABEL RICE FROM THE UNIVERSITY OF KANSAS WITH INSTITUTE PROFESSORS STEPHEN ZUBRICK AND CATE TAYLOR

Being able to tell mum and dad you're hungry, angry or hurting is a fundamental need for every child. The ability to converse is not merely a "nice to have" skill – it's critical in every child's development.

And it has life-long effects. As adults, the ability to use language is also instrumental in whether or not they can succeed in getting an education and later, a job.

"Language is both a developmental outcome and a developmental means for literacy, education and employment," says Professor Cate Taylor. "It's a tool for life."

LOOKING at Language is a world-first study looking at the language development of 2000 Western Australian children, assessing their progress in literacy and language from infancy right through to their teenage years.

Professor Taylor and Winthrop Professor Stephen Zubrick from the Telethon Institute are collaborating with Professor Mabel Rice from the University of Kansas and Professor Shelley Smith from the University of Nebraska Medical Center.

Data for the study are all collected in Western Australia and include 800 families with twins. As well as collecting genetic and environmental data, researchers have conducted formal language tests with the children and also assessed their parents and siblings.

Professor Cate Taylor says the study was the first, large-scale project to investigate causes of early language delay in two-year-old children – and some findings were surprising.

"It was assumed that there was a strong environmental influence – parental education, socio economic status were viewed as being the main drivers of differences in language," says Professor Taylor.

"Our study showed that at the very beginning stages of language it's really more about the child's neurobiology that influences the onset. And that makes sense now from a maturational point of view – try and get a young child to talk before they're ready and they just can't do it.

"There's a real biology driving language development in the early

stages. That was a great relief to parents and grandparents to hear that message!"

The study's long-term research also revealed that of the children identified as "late talkers" at two years of age, 80 per cent had caught up by age seven. As well, that while 70 per cent of "late talkers" are boys, by the age of seven there's no gender difference.

Yet another finding also provided a reminder that children's developmental challenges aren't all evident at the same age. For example, 11 per cent of children who met their language milestones at two years were identified with language problems at seven years.

"So being late to start to talk is not the only pathway to language impairment," explains Professor Taylor. "To focus all our efforts on the two-year-olds, we're going to mostly be treating children who'd catch up anyway and we're going to miss 11 per cent of children who develop language difficulties later on."

A new innovation in the current funding period (2012 – 2017), will be to track children's pathways through school using Australia's National Assessment of Literacy and Numeracy (NAPLAN) data. The study will also provide a previously unavailable insight into the increasing influence of social technology such as computers, mobile phones and the internet on language and learning in adolescence.

Another key collaboration for Professor Taylor is working with

the Tasmanian Early Years Foundation and the departments of Education and Health in Tasmania to evaluate the effectiveness of 11 child and family centres in that state.

"It's that kind of cross-jurisdictional, "putting our heads together" collaboration around a quite a complex evaluation," she says.

Professor Taylor will also collaborate with the Institute's Dr Sally Brinkman, who is conducting a similar review in South Australia at the Fraser Mustard Centre.





## WORKING TOGETHER: AREST CF

Cystic fibrosis (CF) is the most common inherited life-shortening condition affecting Australians. It affects many body systems but is most devastating in the lungs, significantly reducing a child's quality of life and leading to premature death. For kids with CF, catching a cold can mean a hospital admission and treatment with intravenous antibiotics.

Led by Professor Stephen Stick, the WA arm of the Australian Early Surveillance Team for Cystic Fibrosis (AREST CF), based at the Telethon Institute, is a collaborative group of over 30 doctors, researchers and allied health professionals working Australia-wide to improve the respiratory health of children with CF. Indeed, by working together, they have already changed clinical practice around the world, with doctors in countries as far afield as the Netherlands and the USA adopting their methods.

A key problem for doctors treating children with CF is that lung disease starts at different ages and progresses at a different speeds, even though most children have the same CF gene. The AREST CF team has developed diagnostic tests that show that babies as young as three months of age may have signs of lung damage. So, establishing why cells react the way they do in CF patients and finding ways to delay or prevent the development of CF lung disease is key to the AREST CF research.

The Early Surveillance Program (ESP) studies children in Perth and Melbourne from the time they're diagnosed with cystic fibrosis from just three months of age. Researchers take blood samples, conduct CT scans, lung function tests and assess inflammation as the child grows.

The collaboration between Institute staff, Princess Margaret Hospital and the Royal Melbourne Children's Hospital, is entering its seventh year, giving researchers an enviable, world-class bank of information about children with CF.

In 2012, a \$2.1 million research grant saw data and samples from AREST CF's Early Surveillance Program being combined with cutting-edge technologies employed at the

University of North Carolina to investigate airway biology and infection. It's a smart combination of assets and knowledge that it's hoped will provide important answers about how to best treat or even to prevent CF.

Another part of that puzzle is identifying the role of viruses in damaging lung structure. A successful application for a \$1.2 million grant from the National Health and Medical Research Council will fund a four-year collaboration between the Telethon Institute and the Murdoch Childrens Research Institute in Melbourne. Again, teams working together towards a common purpose.

A new research area for AREST CF is the development of stem cell research aimed at producing respiratory cells that form a protective layer of surface tissue. In yet another project being led by the Institute, researchers are partnering with staff at the University of Western Australia, Monash University and the Walter and Eliza Hall Institute in Melbourne to investigate whether these new cells can be created and used to test new treatments and therapies or even re-grow areas of damaged lung.

Over time, the WA arm of AREST CF has established strong trust with both children with the disease and their families. Still, little is known about the psycho-social effects on families – so another collaboration is investigating this topic, looking to translate scientific findings into practical support and education services for kids with CF and their families.

"We care for the child as part of a family, not just as a pair of lungs" says Dr Clair Lee, the AREST CF Program Manager. "We work closely with the hospital and aim to give our families the best evidence-based care that we can provide".

"We're attacking this disease from all angles and taking our research from the bench to the bedside to the school to the home and that's what makes our group different and special."

PROFESSOR STEPHEN STICK CHECKS UP ON KIAH, WHO HAS CYSTIC FIBROSIS, AT PRINCESS MARGARET HOSPITAL FOR CHILDREN



## WORKING TOGETHER: AUTISM

Over the last half century, the number of children diagnosed with autism spectrum disorders has multiplied 25-fold. Today, one child in every hundred is identified as having autism.

Early intervention is the only known way of improving the futures of these children. But, as many of their parents will tell you, even getting a diagnosis can be a slow and frustrating journey. Few proven methods of identifying young children with the condition means precious time in the crucial learning “window of opportunity” before youngsters start school, has passed.

Now, in an extraordinary collaboration between the best minds in the country – and including a veritable army of researchers from the Telethon Institute - children with autism spectrum disorders will receive even more specialised, scientific attention.

Funded by a \$31 million Federal Government grant, The Cooperative Research Centre for Living with Autism Spectrum Disorders will bring together the most respected autism researchers and scientists from across Australia, including a Telethon Institute team led by the Head of Autism Research, Winthrop Professor Andrew Whitehouse.

The Centre will play a key role in helping to guide children and families to the best health, education and community support programs available.

Dr Whitehouse has described the new national research centre as “a game-changer” offering children with autism spectrum disorders a better start.

“What we’re going to do is try and lower the age of accurate diagnosis,” said Dr Whitehouse. “Rather than diagnosing between three and five years of age, we want to lower that by a year and diagnose between two and four.”

“Once we diagnose earlier, we can then get intervention to children earlier and hopefully promote better outcomes to these children and their families,” he said.

“The other really exciting thing is there are service providers - therapy organisations, ground level people - who are also partners in this bid, so everything we do will be rolled out into the clinic.”

The Cooperative Research Centre for Living with Autism Spectrum Disorders will bring together experts from The University of Western Australia, Curtin University, Latrobe University in Melbourne, UNSW in Sydney and the Queensland Institute of Technology. Dr Whitehouse believes the collaboration is key and will lead to significant advances.

“Working with another group doesn’t just double your productivity, it absolutely multiplies your productivity. You can achieve so much more with two, three, four groups than you can with just one, so collaboration is absolutely vital not only for the functioning and existence of research but for actual progression of what we hope to achieve.”

On top of this, the Institute’s autism spectrum disorders team continues to investigate the hows and whys of the condition.

Ongoing research focuses on the pre-natal brain, working to identify brain changes before the baby’s birth, that may signify the risk of autism.

The clinical trials arm of our autism team is also actively developing new and innovative interventions that may help children. For example, the use of a nasal spray containing a hormone that works on the social areas of the brain. Pilot data indicates the use of this naturally-occurring hormone might also be beneficial in developing the social skills of children with autism spectrum disorders.

“Essentially what we say is it opens up their “social pores” and allows increased learning and attention, to happen. It’s great stuff!” said Andrew Whitehouse.

Another study is testing the effectiveness of ipad “apps”, used to complement therapy sessions which are both time-consuming and are often expensive. Technology won’t replace good therapy, but using it as an aid might help. It’s the sort of smart work favoured by Andrew and his innovative team.

“We’re leading Australia with this sort of stuff,” he said.



WINTHROP PROFESSOR ANDREW WHITEHOUSE WITH COOPER, WHO HAS AUTISM.





IN THE OUTPATIENTS CLINIC AT GOROKA GENERAL HOSPITAL, DR CHRIS BLYTH AND HEALTH EXTENSION OFFICER ELIZABETH WILLIAMS EXAMINE A STUDY CHILD WHILE ASSOCIATE PROFESSOR DEBORAH LEHMANN CHATS WITH HIS MUM



## WORKING TOGETHER: PAPUA NEW GUINEA

In Goroka in the highlands of Papua New Guinea, researchers from the Telethon Institute and PNG Institute of Medical Research have been working together since 2005 in the fight against killer infectious diseases.

Papua New Guinea has one of the highest child death rates in the Western Pacific Region - almost one in every 10 children won't reach their fifth birthday - and many will die from pneumonia. Meningitis is another of the top five killers and for those who do survive, the majority will have ongoing problems like blindness, hearing loss and brain damage.

These are illnesses that, thankfully, don't occur too often in Australia due to nationwide vaccination programs. But for our nearest neighbour, immunisations are not yet commonplace and children still die from these vaccine-preventable infections.

The prime suspects for causing pneumonia and meningitis are two common germs, *Streptococcus pneumoniae* and *Haemophilus influenzae* type B (Hib). Studies haven't been done for more than 20 years in Goroka, and in that time a lot has changed - new vaccines and treatments are available, lifestyle is different and there are now better techniques to find out which germs are causing disease.

The Institute's Dr Chris Blyth, who is also an infectious disease paediatrician at Princess Margaret Hospital, is leading a study in Goroka looking at these killer germs. He travels to PNG a couple of times a year to work alongside doctors and nurses at the Goroka General Hospital where recruitment of children into the study takes place.

His team is based in the hospital outpatient clinic, the first port of call for all parents with a sick child. Study nurses examine children suspected of having pneumonia or meningitis and invite them to be part of the study. Once enrolled, blood samples and nose swabs are taken, and if necessary, spinal fluid from lumbar puncture tests. These samples will be compared to nasal swabs from healthy children.

The hospital conditions in PNG are very different from what we know in Australia. The wards swell with children mostly unwell due to infectious diseases like tuberculosis, HIV and pneumonia.

"The doctors here are doing the very best they can with what limited resources they have available to them," Chris says. "I try to visit the wards daily when I'm in PNG to support these hard-working doctors and help where I can."

Chris says that to find ways of preventing and treating these serious illnesses in Papua New Guinean children, first we need to know which germs are causing the disease.

"Other studies done in the highlands of PNG many years ago, identified *Streptococcus pneumoniae* and *Haemophilus influenzae* type B as playing important roles in causing disease," he explains. "We also know that these two germs together are estimated to account for two-thirds of the world's pneumonia and meningitis deaths in children under five."

With these germs building resistance to antibiotics - recent reports suggest 25 per cent of pneumococci isolated from cerebrospinal fluid at Goroka Hospital is resistant to penicillin and 75 per cent of Hib resistant to three core antibiotic drugs - there is an urgent need to monitor the circulating bacteria and re-assess vaccination programs.

"The PNG Government introduced a Hib vaccine in 2008 and will soon implement a nationwide pneumococcal vaccine program. Because we are looking for pneumococcal and Hib germs in our study children, we'll also be able to assess the impact of these vaccination programs."

Chris' study builds upon the years of work already undertaken in PNG by the Institute's Associate Professor Deborah Lehmann. Having spent 17 years living and working in PNG, 12 of those at the PNG Institute of Medical Research, Deborah has a deep affinity with the country and a strong passion to make a difference to its people.

Deborah's work, in collaboration with researchers from PNGIMR, has been looking at the safety and immune response of two different pneumococcal vaccines. It is hoped that in 2014, all children in PNG will be vaccinated against pneumococcal disease, and these study results will inform the government of the safety of both vaccines so that either could be used in the future in PNG as needed.



HEALTH EXTENSION OFFICER  
MAGDELYNE NENIKURO TAKES  
A BLOOD SAMPLE IN THE  
GOROKA CLINIC

"We've been recruiting babies who live within an hour of Goroka to be part of the study," Deborah explains. "It's a big commitment over two years with blood samples, nasal swabs and questionnaires to be completed but all babies receive their full set of immunisations, get transport to and from the clinic and are seen regularly by our excellent medical team."

Dr William Pomat, who completed his PhD at the Telethon Institute and is now Head of Immunology at PNGIMR, says the team is looking at two vaccines, Prevenar 13 and Synflorix, to make sure both work safely and effectively. "The PNG government will roll-out Prevenar 13 soon but we need to be sure that Synflorix will also work well in this country, just in case stocks of Prevenar run out due to world demand," says Dr Pomat.

Deborah says working in a third-world country can be a real challenge.

"The study team literally climbs mountains and crosses rivers to see the babies enrolled in this study," she says. "There are other challenges too such as vehicle and road conditions, rain, erratic electricity and water supplies and the ability to get resources and staff in such a rugged part of the country."

Samples from the study are tested in the bacteriology and immunology laboratories at the PNGIMR while some are sent to Australia for more sophisticated testing. All of the results will help ensure the best vaccines are available for the kids of PNG.

## WORKING TOGETHER: DIABETES

Imagine this – you put your diabetic five-year-old to bed. On her bedside table is an android mobile phone attached to a closed loop pump. As she sleeps, the system monitors her blood sugars and adjusts them automatically. No risk of “hypos”, no late-night finger pricks, no angst. The whole family gets a good night’s sleep.

For the parents of a diabetic child, this sounds like a dream scenario.

Dr Tim Jones and his Diabetes and Obesity Research team are working with engineers in California developing new technologies to make it a reality.

“It’s very cool!” he says.

The “Treat to Range” closed loop system and “Android Home Study” are just two research projects currently being undertaken by Tim and his team at the Telethon Institute. Dr Jones believes harnessing technology and marrying it with world’s best practice in scientific diabetes research could prove life-changing for many affected by the disease.

“What we’re trying to do is to treat diabetes in a way that reduces the burden on the family and reduces the complications of diabetes,” says Dr Jones.

The “Treat to Range” study is the first closed loop project funded in Australia.

“It means it reduces the risk of blood sugar going low and having convulsions and that in turn reduces the anxiety for the family and the stress. It also reduces the time with very high blood sugars, you reduce the long term risk of complications from diabetes - blindness, kidney disease, heart disease.”

The “Predictive Low Glucose” study is another key collaboration, coordinated by the Institute, in which technology will be employed. Using mathematical algorithms, a sensor monitors how the patient’s sugar levels are trending. If they’re either low or high, the monitor is able to predict and react accordingly – all without the patient having to lift (or prick) a finger!

As part of the “Predictive Low Glucose” investigation, 150 children and young adults will be recruited from around Australia. Sites

involved include Princess Margaret Hospital in Perth, Westmead Hospital in Sydney, The Royal Children’s Hospital in Melbourne, The Womens and Childrens Hospital in Adelaide and Newcastle Hospital.

By working together, researchers are able to recruit more broadly. More patients becoming familiar with the technology helps in “getting it out there, getting people using it” says Dr Jones.

Alarming, every year there’s a three per cent increase in the number of children presenting with Type 1 diabetes. “Why?” is also a key question being researched by epidemiologists within the Diabetes and Obesity Team at the Institute who have been examining patterns of Type 1 diabetes in WA as well as getting involved in a national study to look at Type 1 development in detail from conception.

We know that Type 1 diabetes is not caused by lifestyle factors but sadly, we do know what is leading to an increased incidence of Type 2 diabetes among our children – they are mirroring the habits of fatter and more sedentary adults.

“One in four children in Western Australia is obese or overweight,” says Dr Jones. “And increasingly, we’re seeing the development of obesity in primary school-aged children.”

Gastric banding has been shown to help obese adults to lose weight, an ongoing trial at Perth’s Princess Margaret Hospital is assessing the benefits of a balloon placed inside the stomach in those aged 12 to 17. The team is also studying the beneficial effects of exercise in children with Type 2 diabetes.

As well as arresting the incidence of obesity in children, another collaboration between the Diabetes and Obesity team at the Institute and the Department of Human Movement at the University of Western Australia is making new discoveries to help children with insulin treated Type 1 diabetes to exercise safely.

Sometimes, when people with diabetes exercise, burning energy throws their system out – causing hypoglycaemia. Symptoms include sweating and dizziness – it may even cause them to pass out. Naturally, in children, it’s particularly frightening.

“It leads people to be scared to exercise,” says Dr Jones.

By working together with the UWA Human Movement experts, the aim is to come up with guidelines for people with Type 1 Diabetes to help them exercise safely – and in turn, reduce their risk of the long-term complications of diabetes.





## WORKING TOGETHER: RAINE STUDY

More than 20 years ago, nearly 3,000 pregnant women agreed to participate in a new research project looking at the effects of ultrasounds on their unborn baby.

Little would they know how important that decision would be.

While the study found ultrasounds in pregnancy were safe, it was clear that the information that had been gathered in pregnancy and early life could reveal so much more.

Thanks to the extraordinary commitment of these parents and the children, The Raine Study has developed into one of the world's largest and longest studies of pregnancy, child health and development.



Hosted by the Telethon Institute, The Raine Study today is a remarkable collaborative project involving over 2,000 young adults, their parents, Raine Study management and over 25 different research groups across Western Australia, Australia and the world.

The Raine Study participants have been tested, measured and provided information about themselves since birth. Their information has led to new and important discoveries worldwide in areas such as asthma, mental health, nutrition and eye health through to the discovery of new genes.

The Raine Study has established what the normal measurements in children and teenagers are for many outcomes including height, weight, eyesight, liver function and blood test measures. The large number of participants, the many times that they have been assessed and the huge amount of data collected on them over time allows researchers to unravel the complex causes of health and disease.

This year, with participants aged 23, research scientists are involved in three key projects. Researchers from Curtin University and the University of Western Australia in collaboration with the Raine Study team are recording activity levels. Raine participants are fitted with ActiGraph accelerometers for one week, which record all light, moderate and vigorous physical activity, sleep and sedentary behaviour.

Participants' pain and cold thresholds are also being measured, to assess the risk of chronic pain as a reason for work loss. As the participants start their working lives, they are recording how much work time they lose. In this study, researchers will work out how much of young adult work loss is due to poor health – with the aim of finding ways of keeping young workers healthy and productive.

The quality of sleep and its impact on young adults is also a key focus of this year's Raine Study follow-up. While we know that sleep affects aspects of physical and mental wellbeing, little is known about the characteristics of sleep in young adults. Researchers are keen to assess sleep quality in this age group and to identify factors that contribute to sleep disorders like sleep apnoea and even snoring. Previously collected information from

childhood may also identify early life predictors of sleep disorders.

Study participants are invited to spend the night in the Centre for Sleep Science at the University of Western Australia under the watchful gaze of researchers. Hooked up to monitors, machines gauge the length, quality and patterns of participants' sleep. Even fast asleep, the Raine participants are doing their bit for scientific research!

Asthma research has always been a key research area in Raine Study. Major respiratory testing was completed at birth, age six and age 14 – including lung function and allergy testing. While these results were the springboard for trials aiming to prevent the development of asthma during childhood, now researchers have the opportunity to track the disease into adulthood.

Again, when participants come to the Centre for Sleep Science, prior to doing the sleep study, they complete lung function and skin-prick allergy tests. Results will help establish a baseline for the continuing study of chronic respiratory diseases in later life.

The Raine Study has many amazing strengths:

- Over 2,000 participants are still actively involved in the Study
- Over 95,000 measures of health and disease have been collected for every participant
- We have information on over 2.5 million genetic variants.
- Raine participants have been reviewed in detail 11 times - at birth and ages 1, 2, 3, 5, 8, 10, 14, 17, 18, 20 and now at 23.
- We have local, national and international collaborations with multidisciplinary expert researchers.
- The Raine Study is a member of many multi-national consortia where groups of researchers collaborate on a worldwide level looking at specific areas of research.

The Raine Study participants are entering their adult lives, having their own babies and moving into the workforce. Their loyal involvement allows new research opportunities and the continuation of the most valuable collaborative research projects in the world.

## WORKING TOGETHER: CHILDHOOD CANCER

There are few sentences more chilling than “Your child has cancer.”

It’s a diagnosis that sets in train a bewildering array of therapies, hospital visits and aggressive drug treatments designed to give a child the best chance of survival.

But cutting-edge research underway at the Telethon Institute, in conjunction with other experts in other states and other countries, is now multiplying the chances of offering patient-specific treatments.

Research has meant some forms of leukaemia now boast cure rates around 95 per cent, but that’s not the case for babies with the illness, where cures are achieved in around only one third of cases.

“Babies diagnosed at less than 12 months of age have a disease that does not respond well to the current multi-drug therapy and the cure rates have not changed over the last 20 years,” says Professor Ursula Kees, head of the Institute’s Cancer Laboratory.

To address that, Institute researchers have embarked on some important collaborations. Cells taken from leukaemia patients at Princess Margaret Hospital are developed into cell lines which can be used for testing different drugs in the laboratory.

The Children’s Cancer Institute Australia, based in Sydney, has the technology to test 100 different drugs, already approved for use in other cancers, against the Institute’s samples.

“This gives us an insight into whether or not there’s a drug out there that may be more beneficial than what we are currently using for these babies,” says Professor Kees.

A second significant collaboration has seen samples being analysed at the Australian Genome Research Facility to determine the genetic make-up of the cancerous cells.

“Ultimately we should be able to come up with concepts of which combination of drugs may be beneficial for these young babies. It’s not likely to be one wonder-drug, but it’s probably a combination of three or four drugs,” she says.

Similar collaborations are underway in the area of brain tumour research. Our WA experts are also working “hand in glove” with the St Jude Children’s Research Hospital in Memphis, Tennessee as well as at

the Children’s Cancer Institute Australia.

“They’ve got multi-million dollar robots where they can screen thousands of drugs against your cancer cell lines,” says Dr Nick Gottardo who leads the Institute’s Brain Tumour Program.

“We’re testing some of their drug hits against our models.

“Basically, we’re trying to find new drugs that work in the models that we’ve developed and we’re testing other people’s drugs that they’ve come up with in their models to see if they work in our models.”

Instead of using chemotherapy or radiotherapy for every tumour, it’s hoped future treatments will be more specific to the particular genetic make-up of different tumours.

“In other words, trying to find vulnerabilities in the tumour or genetic abnormalities of the tumour and seeing if we can target those with these new drugs,” says Dr Gottardo.

He says collaboration is the only way to go.

“It’s a win-win for everybody. By working together that’s how we will defeat this disease, not by working in silos.”

Indeed, the Division’s newest collaboration commenced after the Telethon Institute was invited to partner with 40 researchers and doctors from five institutions across four Australian states to investigate a malignant brain tumour called glioblastoma.

The Institute will form the paediatric arm of the Brain Cancer Discovery Collaborative, which aims to improve the survival of both children and adults with brain cancer.

“We’ll never defeat this disease by ourselves,” says Dr Gottardo. “Sure, we can make small indents but everyone’s now recognising that if you work as a team and you harness everybody’s strengths...you join everyone and suddenly you have all the right people together to develop new drugs and you can take them through to the clinic.”

Of course, preventing cancer in the first place is always our preference - and here too, the Telethon Institute is conducting first-class, collaborative research.

Epidemiology is the study of patterns and causes of disease. Noted





EMILY, WHO HAS HAD A BRAIN TUMOUR,  
WITH HER BROTHER SAMUEL

cancer epidemiologist, Professor Elizabeth Milne, in collaboration with her research colleagues and paediatric oncologists from around the country, is working to help identify risk factors that may lead to childhood cancers.

This year, Professor Milne has published several articles reporting results from the Australian Study of Childhood Brain Tumours (Aus-CBT) - a nationwide case-control study designed to investigate environmental and genetic risk factors. The research involved over 300 children with brain tumours and their families and around 1000 control families from around Australia.

One recent report described a potential link between professional pesticide treatments in the home and an increased risk of children developing brain tumours.

Another indicated that children of fathers who consume either spirits or high levels of any alcohol (four drinks a day/ 28 drinks a week) around the time of conception have a 50 per cent increase in their risk of the developing a brain tumour.

Another important finding from this study is that the risk of brain tumours is reduced among children of women who take folic acid supplements before and during the pregnancy. As is well known, folic acid also helps to prevent spina bifida.

These findings are shedding new light on possible risk factors for brain tumours in children.

"Very little is known about the causes of childhood cancers and we've done some of the biggest studies internationally on these diseases," says Professor Milne.

"We're looking at all the information we collected from the case and control parents about themselves and their children to identify the factors that may increase the risk of cancers in children. We hope that this information will help to prevent at least some cases of childhood cancers in the future."



## WORKING TOGETHER: FRASER MUSTARD CENTRE

Scientists and child health researchers already know that a child's development in the time before he or she goes to school is instrumental in later life.

Now, an innovative collaboration is taking the newest, proven scientific findings on early childhood, translating them into actions - from education, health and social perspectives - and then working to have them implemented in government policy.

The Fraser Mustard Centre in Adelaide links the Telethon Institute and the South Australian Department of Education and Child Development to work on local projects. It was named in honour of leading Canadian researcher and former Adelaide Thinker-in-Residence the late Dr Fraser Mustard.

"That relationship between the researchers, the policy-makers, the practitioners, and those that do the work in the community, is very unique," says Dr Sally Brinkman, co-founder of The Fraser Mustard Centre.

Previously based at the Telethon Institute in Perth, Sally now heads the Institute's work in Adelaide. Programs include local projects as part of the Fraser Mustard Centre, as well as Institute projects with a national and international focus.

On a local level, the Fraser Mustard Centre is evaluating whether "children's centres" make a difference in child development in pre-school age. In South Australia, these centres offer services like child health nurses, parenting classes, child-care, even pre-school - all in one location.

Sally believes working together with the wider community facilitates greater engagement. Feedback and findings are regularly made public, benefitting both children and their families.

"We're wanting to help them, we want to participate. We want to understand what their needs are, what the barriers are from a political and financial situation, what they're struggling with and then we can make sure that our evaluation is supporting the progress of children as we go along," she says.

And there's no "one size fits all" approach. Indeed, Sally says the concept of what's "normal" and what's "not normal" is quite

different in different cultures.

In Indonesia, where Sally's team is conducting a key international study, a whole new set of standards of measuring child development had to be developed to incorporate differences between the Indonesian children and their Western contemporaries.

Where early literacy can be used as one gauge, in poor communities with inter-generational illiteracy, it's an unrealistic benchmark. Other indicators of development as basic as toileting habits are not universal, either. Whether an Australian child is toilet trained by the age of four or five can be an indication of their progress, it's often different elsewhere.

"In poor Indonesian villages, families can't afford boxed nappies that you can dispose of, so those children are toilet trained as soon as they can walk," says Dr Brinkman. "So to even ask a question about that for a child at three or four years of age would be abhorrent - those parents would think there was something wrong with you"

She developed alternative methods of monitoring child development in Indonesia. The Adelaide team in partnership with the World Bank is conducting a randomised control trial to determine whether children exposed to community-based

playgroup/childcare centres are better prepared for school. The World Bank-financed program helped establish approximately 6,000 centers in poor communities across Indonesia. To date, more than half a million children aged 0 to 6 have attended these centers.

An important collaboration within Australia is a \$1.5 million contract won by the Adelaide team to undertake research around the Australian Early Development Index, for the Federal Department of Education, Employment and Workplace Relations.

Essentially, the AEDI is an audit of child development and Sally conducted the first pilot study in Perth back in 2002 with just a small number of children. Now operating nationally, the AEDI is an important tool used by decision makers all over Australia.

"From small communities to the whole country, people are using it to see how their children are going over time," says Dr Brinkman. "We're wanting to know what is it that predicts the AEDI? What can people and communities do to improve their results?"

"So much of our research goes from testing the validity of instruments through to how do we make changes? How do we improve developmental outcomes in children?"

LOUISA SANTUCCI, TESS GREGORY, SALLY BRINKMAN, YASMIN HARMAN-SMITH, ANGELA KINNELL AND VERONICA SMYTH



## WORKING TOGETHER: DEVELOPMENTAL PATHWAYS

The first step in identifying – and perhaps, even solving – any problem is to get all the facts.

The Developmental Pathways in WA Children Project (DPP) takes data gathered by 10 government departments and agencies and uses it to investigate both risk and protective factors leading to developmental outcomes for children and young people.

Additionally, the data are used for evaluation and to identify where government resources and services are best positioned.

Essentially, taking the facts, in the form of de-identified, linked, population data and using it to come up with different - and better - ways of helping young people to develop in a positive way and helping government make evidence based decisions.

The Telethon Institute is also dedicated to translating the research findings into policy and practice that will lead to “whole of government” interventions.

Collaborative by its nature, the DPP has been involved in some exciting research programs this year in areas as diverse as Attention Deficit Hyperactivity Disorder (ADHD), and juvenile offending.

Prompted by an escalation in the number of children presenting with ADHD in WA, Dr Desiree Silva has commenced a PhD through the Institute and the University of Western Australia investigating the risk factors and outcomes of children and adolescents diagnosed with ADHD.

A Professor of Paediatric Medicine, Dr Silva is using DPP data and questionnaires to determine if there are any antenatal or neonatal risk factors common to children who later require stimulant medication to treat ADHD, as well as investigating the impact of stimulant medication on children’s outcomes. She’s also investigating whether these children have more hospital visits, accidents, or criminal and antisocial behaviour issues.

Similarly, Jocelyn Jones is completing her doctorate using DPP data to explore whether by identifying both risk and protective behaviours, and implementing different support strategies, will

lead to Aboriginal and Torres Strait Islander children having fewer contacts with the juvenile justice system.

Associate Professor Anna Ferrante is undertaking a population-based study of the dimensions and development of offending among Western Australian children.

This project is hoping to give researchers a better understanding of the dimensions of juvenile offending and of the impact of various factors on the development of offending over the course of a child’s life.

By identifying the link between risk factors and their effect on offending, it may be possible to map “pathways” from early childhood to juvenile offending and later criminal behaviour. Conversely, it may also be possible to identify alternate pathways that prevent this behavior escalating.

“The work done by our researchers on the Developmental Pathways Project is ground-breaking,” says Program Manager Dr Rebecca Glauert. “We have a focus on prevention, and we want to ensure that every child has the best chance at a happy, healthy life. We are using real data to get real solutions.”

WA is one of the few places in the world that has the depth and breadth of information afforded by population-level data. But it is the ability to translate the findings into policy and practice that makes the Developmental Pathways Project innovative on an international scale.

By working together, it allows a “big picture” of areas of child research including mental and physical health, child abuse and neglect, alcohol and drug use, juvenile offending, disability, education and housing. Overlapping areas of research also means the complex nature of issues affecting the development of Australian children can be addressed.

“This project is all about collaboration,” says Dr Glauert. “We have worked with our Government agency partners from the very beginning, finding out what the most pressing concerns they have about WA children, then investigating what we can do to try

to prevent those negative outcomes, and then feeding back our results to people who can implement a change.”

“It’s all about the relationships we have with our partners. We trust each other. We all want the same outcome - healthier, happier children.”





## WORKING TOGETHER: INFECTIOUS DISEASE

In the competitive world of scientific research, an inquiring mind is an obvious necessity, a “generosity of spirit” is another key requirement, according to the Director of the Telethon Institute and infectious diseases expert Professor Jonathan Carapetis.

“Collaboration and partnership will be the way of the future,” he says.

Professor Carapetis leads by example. In his own research focusing on rheumatic heart disease, he works with investigators around Australia and around the world. He is also a member of a Geneva-based think-tank researching and advocating on behalf of those with the disease.

“It’s a very broad program of work, aimed at tackling pretty much all of the different parts of a puzzle that go to controlling this disease which is a major problem in the Aboriginal population in Australia,” he says.

“It’s a disease of poverty and social injustice but it’s a disease we can do something about, both in terms of socio-economic concerns like better housing but also there’s medical things we can do to control it. It’s an infectious disease that becomes a chronic disease.”

Professor Carapetis is currently involved in several key collaborations. Two studies in the Northern Territory are assessing the effect of a health service intervention to improve care in Aboriginal health centres and the genetic foundations of the disease in 500 patients with rheumatic heart disease and 1,000 healthy controls.

A separate collaboration with the Walter and Eliza Hall Institute is researching the pathogenesis of the disease. Yet another with the University of New South Wales is investigating the disease in pregnancy.

Throughout the infectious disease research projects at the Telethon Institute, many other important collaborations are underway.

Associate Professor Deborah Lehmann continues to lead ground-breaking work on otitis media – a middle ear infection, especially

prevalent in Aboriginal children. Untreated, it can lead to hearing loss which has ongoing implications for childhood development, school performance and subsequent social and economic wellbeing.

Working with the WA Health Promotion Foundation the “Good Ears Good Learning” program is using some novel ways to encourage a change in community habits and awareness.

These include a giant inflatable ear that children can walk through, soap-making workshops to encourage hand-washing, even music workshops with themes of keeping cigarette smoke away from children and the importance of regular ear screening.

And early results were very positive – a 25 per cent increase in the number of people reporting they now only smoke outside the home. Fewer participants now smoke in the car. The number of community members who understood the importance of washing their hands doubled. They reported they are now doing it more frequently.

Among health workers and nurses too, there were significant changes in their screening methods and increased vigilance about treating the disease.

The Vaccine Trials Group, headed by Associate Professor Peter Richmond, is also working on many diverse and exciting programs.

One is examining the effectiveness of using a cystic fibrosis treatment on children with otitis media. Even after grommets have been inserted, “glue” in the middle ear can hinder treatment and cause recurrent infections.

The Institute, Princess Margaret Hospital and the WA Government State Health Research Advisory Council are working together on a trial that will test whether the CF treatment will dissolve “glue” in the ear, reducing the need for multiple surgeries.

Another project sees the Institute’s communicable disease specialist and microbiologist Associate Professor Chris Blyth collaborating with various divisions of the WA Department of Health and PathWest on the WAIVE and FAST studies. Initiated to monitor the effectiveness and safety of influenza vaccines in

young children, the studies have enrolled more than 2,500 and 900 preschool children respectively. Interim findings showed the vaccine is effective in this age group. In 2012, this study was also extended to include pregnant women. Again, interim data are reassuring.

A more unconventional collaboration has come in the form of the Allegra Scafidas Pneumococcal Laboratory, established in memory of little Allegra who died of pneumococcal meningitis. Specialised equipment is facilitating unique work, with researchers working towards developing a vaccine to immunise against all pneumococcal strains.

PROFESSOR JONATHAN CARAPETIS WITH HOPE, A RHEUMATIC HEART DISEASE PATIENT AT PRINCESS MARGARET HOSPITAL





# FACULTY AND PRE-FACULTY

The Faculty is the senior research leadership group of the Institute and 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 meet some but not all of the required activities for Faculty and are 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  
 Jonathan Carapetis  
 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

Eve Blair  
 Nick Gottardo  
 Graham Hall  
 David Lawrence  
 Elizabeth Milne  
 Wendy Oddy  
 Roz Walker  
 Andrew Whitehouse  
 Graeme Zosky

### PROGRAM MANAGER

Sally Brinkman  
 Kim Carter  
 Rebecca Glauert  
 Richard Hopkins  
 Tanyana Jackiewicz  
 Peter Jacoby  
 Jenny Mountain  
 Jan Payne  
 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



**JONATHAN CARAPETIS**  
 MBBS FRACP FAFPHM PhD

- Research interests:
- Rheumatic fever/heart disease
  - Group A streptococcal diseases
  - Vaccine preventable disease
  - Indigenous child health
  - Child/youth development, health and education
  - Skin sores and scabies



**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
  - Twin studies
  - Clinical trials
  - Research design



**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 lung diseases
- Immune regulation at mucosal surfaces
- Developmental immunology
- Paediatric vaccinology
- Asthma treatment and prevention
- 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 HonUniv HonMD  
HonFRACGP HonFRCPC 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
- Recombinant DNA and peptide technology



**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



**EVE BLAIR**  
BSc(Hons) PhD PhD

Research interests:

- Perinatal & paediatric epidemiology
- Cerebral palsy aetiology and management
- Intrauterine growth: measurement, determinants and outcomes
- Epidemiological methods



**NICK GOTTARDO**  
MB ChB FRACP(Paed) PhD

Research interests:

- Childhood brain tumours
- Translational research
- Molecular targeted therapies
- Drug resistance





**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:

- Mental health
- Diet, nutrition, physical activity, metabolism and obesity
- Evidence-based preventive health
- Smoking & substance use disorders
- Survey methods and development
- Human capability expansion



**ELIZABETH MILNE**  
BSc MPH PhD

Research interests:

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



**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
- Qualitative research



**ANDREW WHITEHOUSE**  
BSc(Hons) PhD

Research interests:

- Autism
- Developmental disorders
- Child development
- Treatments and interventions
- Randomised controlled trials



**GRAEME ZOSKY**  
PhD MBIostat

Research interests:

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



**SALLY BRINKMAN**  
BA MPH PhD

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



**REBECCA GLAUERT**  
BA Psy(Hons) PhD

Research interests:

- Child development
- Mental health
- Data linkage
- Education
- Knowledge translation



**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



**PETER JACOBY**  
BA(Hons) MSc

- Research interests:
- Biostatistics
  - Infectious diseases
  - Pre-term birth
  - Growth
  - Epilepsy
  - Epidemiology



**JENNY MOUNTAIN**  
BA MBA MCLinEpi

- Research interests:
- Longitudinal cohort studies
  - Project management
  - Study design
  - Communication
  - Adolescent research
  - Clinical epidemiology



**JAN PAYNE**  
SRN (UKCC) PostGrad Dip (Health Admin)  
MSc PhD

- Research interests:
- Epidemiology of fetal alcohol spectrum disorders
  - Alcohol consumption in pregnancy
  - Consumer and community involvement in research
  - Research project management



**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

**PRE-FACULTY**

<b>ASSOCIATE PRINCIPAL INVESTIGATOR</b>	<b>ASSOCIATE PROGRAM MANAGER</b>
Karina Allen	Tatjana Heinrich
Alex Beesley	Katrin Hoffman
Christopher Blyth	Clair Lee
Anthony Bosco	Nadia Milech
Saskia Decuyper	Francis Mitrou
Jenny Downs	
Kristjana Einarsdottir	
Raelene Endersby	
Shelley Gorman	
Belinda Hales	
Sarra Jamieson	
Anthony Kicic	
Alexander Larcombe	
Melissa O'Donnell	
Monique Robinson	
Deborah Strickland	
Jason Waithman	



**KARINA ALLEN**  
BA(Hons) MPsych (Clinical) PhD

- Research interests:
- Eating and weight disorders
  - Mental health
  - Prevention and early intervention
  - Clinical trials
  - Translational research
  - Public health



**ALEX BEESLEY**  
BSc(Hons) PhD

- Research interests:
- Cancer biology
  - Drug resistance
  - Genomic technologies
  - Novel therapies



**CHRISTOPHER BLYTH**  
MBBS(Hons) FRACP FRCPA

- Research interests:
- Influenza
  - Upper and lower respiratory tract infection
  - Pneumonia
  - Emerging respiratory pathogens
  - Vaccine preventable infections and vaccine safety



**ANTHONY BOSCO**  
PhD

- Research interests:
- Asthma
  - Genomics
  - Immunology
  - Systems biology





**SASKIA DECUYPERE**

MSc PhD

Research interests:

- Infectious diseases
- Diagnostic development
- Metabolomics
- Translational research
- Tropical medicine



**JENNY DOWNS**

BAppSc(Physio) MSc PhD

Research interests:

- Disability
- Rett syndrome
- CDKL5 disorder
- Early onset scoliosis
- Rare disorders



**KRISTJANA EINARSDOTTIR**

BSc(Hons) PhD

Research interests:

- Perinatal health
- Health services research



**RAELENE ENDERSBY**

BSc(Hons) PhD

Research interests:

- Childhood brain tumours
- Pten Hamartoma Tumour Syndrome/Cowden's disease
- Development neurobiology
- Translational medicine
- Animal models of cancer
- Signal Transduction Pathways



**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



**BELINDA HALES**

BSc(Hons) PhD

Research interests:

- Asthma
- Allergy
- Infectious disease
- Immunology



**SARRA JAMIESON**

BSc MSc PhD

Research interests:

- Genetic Epidemiology
- Epigenetics
- Otitis Media
- Hypospadias
- Congenital Toxoplasmosis



**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



**ALEXANDER LARCOMBE**

BSc(Env)Hons PhD

Research interests:

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



**MELISSA O'DONNELL**

BPsych(Hons) DipEd MPsych PhD

Research interests:

- Child maltreatment
- Linked data
- Mental health
- Epidemiology



**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
- Pre-term birth



**JASON WAITHMAN**  
BSc PhD

- Research interests:
- Dendritic cells
  - T cells
  - Melanoma
  - Adjuvant therapy
  - Basic Immunology



**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



**KATRIN HOFFMANN**  
PhD

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



**CLAIR LEE**  
BSc(Hons) 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
  - Intracellular & phenotypic drug targets
  - Cell penetrating peptides
  - Neurotrauma and brain tumours
  - Cancer, ischaemia & inflammation



**FRANCIS MITROU**  
BEC

- Research interests:
- Social determinants of health and wellbeing
  - Health economics
  - Indigenous disadvantage
  - Mental health and tobacco use
  - Human capability across the lifecycle

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

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





# RESEARCH LEADERSHIP PROGRAM

A forward-thinking leadership program, developed in collaboration with Organisational and Staff Development Services at the University of Western Australia (UWA), aimed at developing future research leaders has earned the Telethon Institute a national award for excellence.

The 2012 ARMS Awards for Excellence, presented by the Australasian Research Management Society, recognised our achievements in the category of 'Research Management Innovation' for its creation of a highly successful leadership program aimed at developing and nurturing the Institute's next generation of scientists.

The Telethon Institute's inaugural 'Research Leadership Program' was rolled out in 2011/12 with the aim of providing leadership training, professional development, peer support, workshops,

mentoring and networking to outstanding early-mid career researchers, developing their skills to help them lead the Telethon Institute in the years to come.

Feedback and research shows too often researchers with an outstanding research track record find themselves in leadership roles with no experience or training in leading teams, communicating with funding bodies, donors, senior academic and industry partners or even politicians and bureaucrats, and no peer support.

To overcome this, early-mid career researchers at the Institute who demonstrated outstanding leadership potential were selected in the program. Nominations for the program were judged by an independent committee and the following researchers were selected:

## 2011/2012

Alex Beesley  
Anthony Bosco  
Raelene Endersby  
Belinda Hales  
Graham Hall  
Melissa O'Donnell  
Christopher Peacock  
Deborah Strickland  
Andrew Whitehouse  
Graeme Zosky

## 2012/2013

Kim Carter  
Saskia Decuypere  
Jenny Downs  
Emma Glasson  
Shelley Gorman  
Sarra Jamieson  
Alex Larcombe  
Monique Robinson



The year-long program comprises a series of workshops and meetings including 360 degree leadership profiling, support for interstate mentoring, a variety of professional development and career management workshops, leadership projects, meetings with community and business leaders including Therese Rein, Jon Burgess and Steve Dorlandt, and representation of the Institute at VIP functions and peer support.

*"We feel the program was a resounding success..it is impossible to quantify the lessons we learnt, the advice we soaked up, the camaraderie we developed and the insights we achieved."*

Letter of thanks from the inaugural Research Leadership Team to the Institute Board

LEFT TO RIGHT: KIM CARTER, ALEX LARCOMBE, KATHY VIAL, SASKIA DECUYPERE, EMMA GLASSON, NICK NORTHCOTT, JONATHAN CARAPETIS, SARRA JAMIESON, JENNY DOWNS, MOIRA CLAY, MONIQUE ROBINSON AND SHELLEY GORMAN

# SUPPORTING RESEARCHERS AND STUDENTS

## Postdoctoral Council

Previously known as the Postdoctoral Researchers Group, the re-named Postdoctoral Council continues to provide a voice for early and mid-career researchers and support for the progression of their careers.

Along with a name change, the Council has been reorganised into subcommittees to better coordinate key events and activities including the postdoctoral mentoring program, funding opportunities, communication with the wider postdoctoral group, visiting speaker program and social and networking opportunities.

The group continued to make an impact in 2012 by providing significant input into key Institute policy and planning, as well as organising the Inaugural Early Career Researcher Retreat held in June at the Flying Squadron Yacht Club.

Retreat organisers, Hannah Moore, Ruth Thornton and Jacqueline McGlade, are to be congratulated for coordinating an event which included 20 guest speakers from the Institute and further afield and five information sessions covering fellowship and funding; grant panels and peer reviews; funding rules and salary support; being a successful researcher; and future support. The Retreat was well attended by researchers from the Telethon Institute, Princess Margaret Hospital and UWA School of Paediatrics and Child Health who had five or less years of postdoctoral experience.



Other key events during 2012 included a postdoctoral survey and an end of year function with Institute Director Jonathan Carapetis.

Thanks to Postdoctoral Council members - Raelene Endersby (Chair), Monique Robinson (Deputy Chair), Belinda Hales, Alex Larcombe, Alex Gout, Nadia Milech, Amy Samuels, Andrew Whitehouse, Sarra Jamieson, Rebecca Glauert, Kim Carter, Peter Dallas, Katherine Thompson and Geoff Hammond.

## Student Circle

The Telethon Institute is home to close to 100 Honours, Masters and PhD researchers undertaking research in a diverse range of areas from asthma, allergies and respiratory diseases, to working with populations of people with disabilities and rare diseases.

Our aim is to provide these students, our future research leaders, with a learning environment where their research work is challenging, where they will be effectively mentored and immersed in a culture of excellence and supported by an active student body called the Student Circle.

The Student Circle is run by students and focuses on student issues, challenges and triumphs. Members are from the Telethon Institute, UWA School of Paediatrics and Child Health, Princess Margaret Hospital and King Edward Memorial Hospital.

The Student Circle committee meets monthly to discuss relevant events occurring in the research and general community, share experiences and generally touch-base and catch up with each other. The group also provides feedback to the Student Reference Group.

In April 2012, to further expand and strengthen the bonds and communication between our postgraduate students, the Student Circle held the Inaugural Student Circle Development Program on Rottne Island. This event was a great success attended by 40 students and featuring six invited speakers who talked about career path options.

EARLY CAREER RESEARCHER RETREAT: KATHY VIAL, HANNAH MOORE, JACQUELINE MCGLADE, RUTH THORNTON, MARIA KAVALLARIS (GUEST SPEAKER) AND MOIRA CLAY

STUDENT CIRCLE: ASHLEY SCHOOF, KITTY FOLEY, ALEX HEATON AND STEPHANIE FEHR



In 2012, the students organised the 6th Annual Student Symposium which delivered a full program of events with over 30 student presentations, guest speakers and presentations. Highlights included a discussion by Jonathan Carapetis providing insights into his career path culminating in becoming Director of the Institute and a presentation by Professor Mike Daube about advocacy for change in public health policy.

During 2012, the Student Circle agreed to take part in the Mentoring Program offered by True Blue Dreaming which involves mentoring high school students in rural and remote communities.

Postgraduate students will be making four trips to Derby in 2013 and the expectation is the students will develop a relationship with the high school students which will see them working together to complete a project (likely to include establishment of a school garden).

Thanks to the Student Circle organising committee – Stephanie Fehr, Kitty Foley, Alex Heaton (School of Paediatrics and Child Health) and Ashley Schoof.



# CONSUMER AND COMMUNITY PARTICIPATION

The consumer and community participation program at the Institute continued to develop and lead the way during 2012. The program, jointly operated with the University of Western Australia's School of Population Health, delivered on a long list of activities and achievements which were made possible by the ongoing and valued input and support of researchers, consumers and community members.

## Consumer and Community Advisory Council

The task of enhancing the quality and relevance of research undertaken at the Telethon Institute falls to the Consumer and Community Advisory Council. The Council consists of consumers, community members, researchers and management from the Institute. During 2012 the Council was involved in a wide range of activities which included:

- attendance at the International Data Linkage conference held in May
- attendance at the public consultation for the National Review of Health and Medical Research in Australia
- involvement in the development of the internal Grant Application Review Process at the Institute
- input into the development of the Community Conversation on Strategic Planning
- attendance at the Consumer Health Forum of Australia national consumer consultation for the National Health and Medical Research Council's Statement on Consumer and Community Participation

Julie Ireland, an inaugural member and Chairperson since 2010, finished her term on the Council in December. Her contribution to the Institute over the past 20 years in the area of Down Syndrome research and more recently to the Council has been outstanding.

The Consumer and Community Participation Award for 2012 was presented to Fiona Stanley, Steve Zubrick, Carol Bower, Helen Leonard, Nick De Klerk, Sven Silburn, Jan Payne, Leanne Scott, and members of the National Health and Medical Research Council Program Grant Governance Committee for their support and commitment to developing a "good practice" model for implementing consumer and community participation within a large and diverse program of research.

Peter Franklin was recognised for his work in involving the community in all aspects of the Kwinana Respiratory Study.



AWARD WINNERS JAN PAYNE, HELEN LEONARD, LEANNE SCOTT, CAROL BOWER AND COUNCIL CHAIR JULIE IRELAND

## Consumer and Community Participation Unit

The joint Telethon Institute and UWA School of Population Health consumer and community participation program enjoyed a continued rise in awareness and reach during 2012. Staff presented the program at six local, eight national and four international conferences and meetings. Anne McKenzie, the Institute's Consumer Advocate, was invited to join a working committee to draft the 2nd Statement on Consumer and Community Participation in Health and Medical Research.

## Participation Network

Established in February 2012, the Participation Network gained an early milestone when 120 consumer and community members from across Western Australia, with links to 86 consumer and community organisations, signed up to receive ongoing information about opportunities to be involved in research projects, information on current and new research projects, hot topics and issues.

A national Alliance Network has also been established to inform consumers and community organisations from across Australia about the Participation Program's activities. The newsletter 'Network News' will be sent quarterly to all members.

## Involving People in Research website

The Involving People in Research website was viewed by over 1700 visitors from 37 countries, including visitors from the top 100 universities as ranked by the Academic Ranking of World Universities.

## Researcher training workshops

We held two consumer and five researcher training workshops on consumer and community engagement, bringing the total number of people who have attended our training to over 900 people from across Australia.

## Community Conversations

We actively continue to support a collaborative approach between researchers, consumers and community members who have an interest in the research being studied. In 2012, 70 consumer and community members attended four Community Conversations:

- Broome Community Forum discussed changes to the Cerebral Palsy Register following legislative changes for mandatory notification of birth anomalies
- Stress in Pregnancy Community Conversation looked at the effects of messages in the media on pregnant women
- Pre-term Birth Community Conversation discussed current research being undertaken on risks
- What's Our Vision Community Conversation brought together senior consumer representatives and community leaders from a wide range of non-government community organisations to have input into the development of the Institute's Strategic Plan.



BROOME COMMUNITY CONVERSATION

ANNE MCKENZIE AND BEN HORGAN



## Ben's passion to support research

Diagnosed at two with juvenile arthritis, Ben Horgan asked "why" often. This quest for answers and understanding ignited a life-long passion to support research and a desire to give back to the health care industry that has supported him since childhood.

In 2005, Ben became the inaugural Chair of the Institute's Consumer and Community Advisory Council and steered the group to establish mechanisms for consumers and community to be actively involved in the research the Institute conducts. A role he describes as "rewarding, exciting and fun".

"Researchers are fascinating people and I enjoy being involved in their many research projects," says Ben. "It is exciting to be able to give guidance, opinions and feedback and rewarding to be able to reach out to other community members."

Ben believes the Telethon Institute is one of the leading research organisations on community engagement and credits the results to Anne McKenzie, the Institute's Consumer Advocate, and her team.

"Our achievements would not be possible without Anne and it is due to her passion and hard work over a long period of time that we have such a unique community engagement program. I am blessed to have had the opportunity to work with her and her team," said Ben.

Ben would love to see the success story of the Institute's

community engagement program taken all around Australia and the world.

"It would be great to see other research institutes and organisations understand and value the importance of community engagement when designing, implementing and communicating the findings of their research and the Telethon Institute is leading the way in this area."

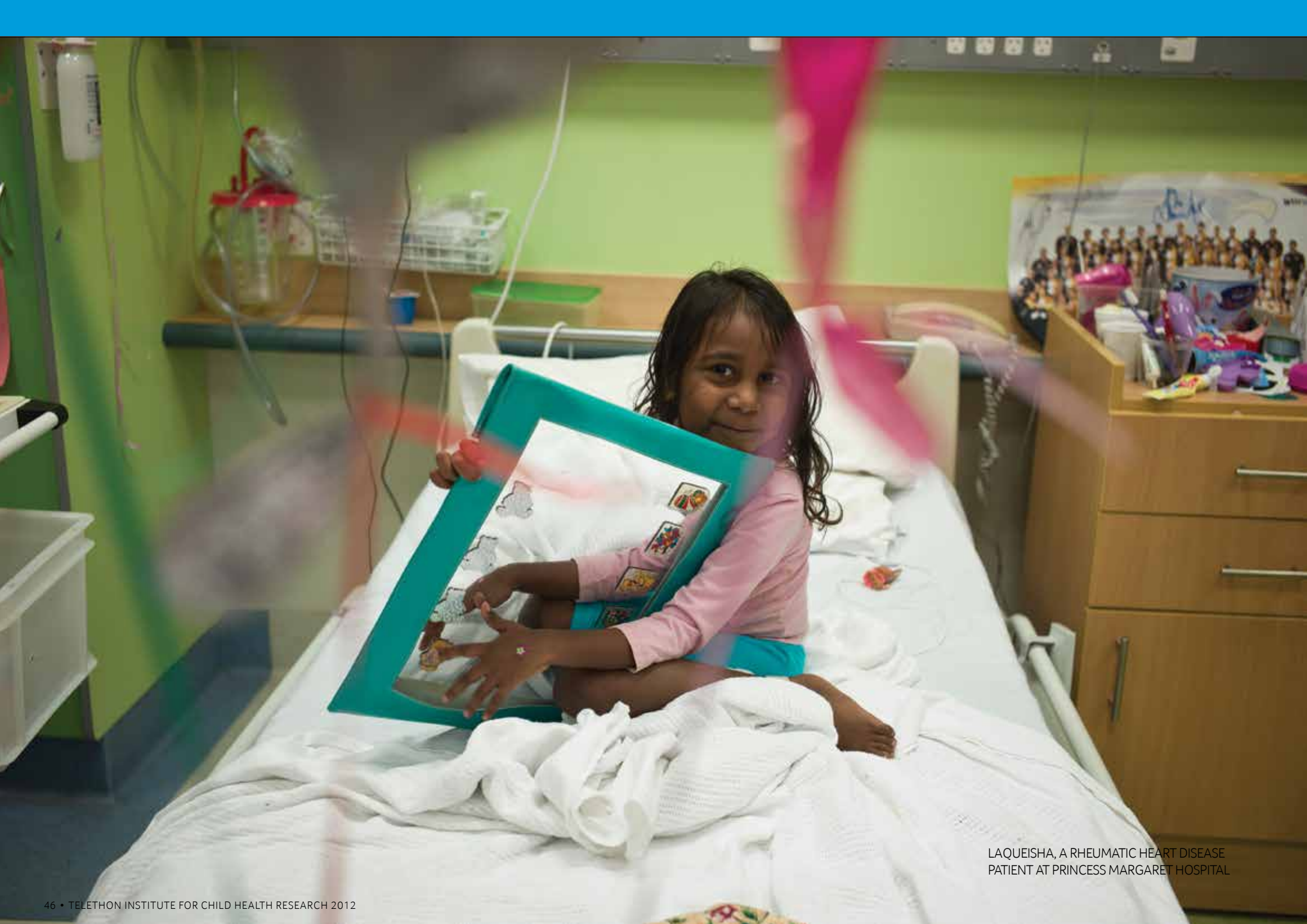
"My hope is to stay involved with the Participation Unit's Community Network and support the next wave of council members and consumer advocates, in particular the young people involved in the Raine Study," said Ben.

"They are an exciting bunch to be around and the future for this project lies in the enthusiasm of the next wave of advocates to follow through and use the framework we have set up."

Ben believes when everybody is on board we all have a win. In the long-term, Ben hopes other people with a chronic illness will become involved in research through the framework.

"People with a chronic illness have unique insights to share and by working together everyone achieves more."





LAQUEISHA, A RHEUMATIC HEART DISEASE PATIENT AT PRINCESS MARGARET HOSPITAL

# WORKING TOGETHER TO IMPROVE ABORIGINAL CHILD HEALTH

From its inception, the Institute has made a commitment to Aboriginal communities to work with them and in partnership with the Aboriginal Community Controlled Health Services (ACCHS) to positively change the unacceptable health and wellbeing status of Aboriginal families in Western Australia. The Centre for Research Excellence in Aboriginal Health and Wellbeing (CREAHW) began in 2010 based at the Telethon Institute in partnership with Murdoch University, Curtin University, University of Western Australia, Pindi Pindi, Baker IDI and the Combined Universities Centre for Rural Health. This five-year program is currently the centrepiece of a range of Aboriginal research projects at the Institute.

But with the new Strategic Plan came an opportunity to revisit our vision for Aboriginal health research as well. A comprehensive consultancy and review, instigated during 2012, has outlined a number of priority areas to ensure the ongoing effectiveness of our Aboriginal research programs. These will be encapsulated in a separate statement on the Institute's commitment to Aboriginal research, to be released in 2013. The priorities already identified include:

- that the Aboriginal health research agenda is embedded in all child health themes and with shared ownership across the Institute
- providing better systems and resources to develop and support all aspects of Aboriginal health research at the Institute
- that the Institute increases and develops the capacity of its Aboriginal workforce and works to improve the capacity of the Aboriginal health workforce in WA to understand and participate in research.
- Aboriginal health research priorities are developed with the participation of Aboriginal organisations and in line with Aboriginal processes
- research projects and findings are communicated effectively and efficiently to government and community
- that the Institute publically acknowledge that it is located on Nyoongar Wadjuk Boodja (land).

The Telethon Institute thanks all the individuals and organisations that contributed to the consultation process.

One of our major activities over 2012 was our work with the Aboriginal Health Council of WA (AHCWA) and the UWA's Rural Clinical School of WA (RCSWA) to establish a WA Aboriginal Health Knowledge Network (WAAHKN). Funding from Rio Tinto allowed the Network partners to undertake the consultation and design phase and included funding to send a small delegation to Alaska and Canada to identify and consider other possible community-based research models.



# COLLABORATIONS

Helen Keller once said, “Alone we can do so little; together we can do so much.”

Our researchers have forged strategic collaborations with researchers in their fields at major universities and institutes around the world. By working together, we have a greater opportunity to improve the lives of children, young people, families and communities in Western Australia and beyond.

Some of our key research collaborations are listed below.

## International

Addenbrooke’s Hospital (UK)

Banarus Hindu University (India)

Bern University Hospital (Switzerland)

Cambridge University (UK)

Children’s Research Institute (USA)

Clinical Research Unit Nanoro (Burkina Faso)

Erasmus University (The Netherlands)

Erasmus University Medical Centre (The Netherlands)

Goroka General Hospital (Papua New Guinea)

Hospital for Sick Children (Canada)

Hospital Universitário (Brazil)

Institute for Child Health (UK)

Institute of Tropical Medicine Antwerp (Belgium)

Karolinska Institute (Sweden)

Khon Kaen University (Thailand)

Mahidol University (Thailand)

Mount Sinai School of Medicine (USA)

Medical Research Council Harwell (UK)

National Heart & Lung Institute (UK)

National Institutes of Health (USA)

Newcastle University (UK)

Papua New Guinea Institute of Medical Research  
(Papua New Guinea)

St Jude Children’s Research Hospital (USA)

St Louis Children’s Hospital (USA)

Universidade Federal do Rio Grande do Norte (Brazil)

University Children Hospital (Austria)

University Children Hospital (Switzerland)

University Hospital of South Manchester (UK)

University of Arizona (USA)

University of British Columbia (Canada)

University of California (USA)

University of Cambridge (UK)

University of Iowa (USA)

University of Massachusetts Medical School (USA)

University of North Carolina (USA)

University of Oxford (UK)

University of Szeged (Hungary)

University Of Wisconsin Medical School (USA)

Upper Airway Research Laboratory (Belgium)

Washington University (USA)

Wellcome Trust Sanger Institute (UK)

Wisconsin University (USA)

Women and Brigham’s Hospital (USA)





Australian

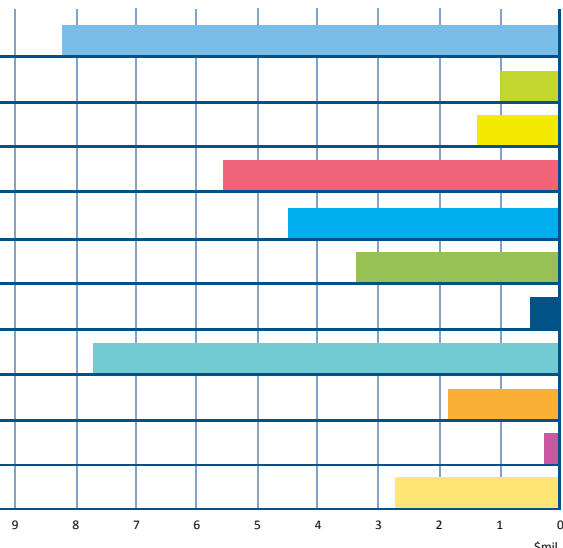
- Australasian Society for Infectious Diseases Clinical Research Network (NSW)
- Australian Clinical Trials Network (NSW)
- Australian National University (ACT)
- Australian Neuromuscular Research Institute (WA)
- Centre for Cancer Biology (SA)
- Children’s Cancer Institute Australia for Medical Research (NSW)
- Children’s Hospital Westmead (NSW)
- Curtin University (WA)
- Edith Cowan University (WA)
- Hollywood Medical Centre (WA)
- James Cook University (QLD)
- King Edward Memorial Hospital (WA)

- Melbourne University (VIC)
- Menzies School of Health Research (NT)
- Monash Institute for Medical Research (VIC)
- Monash University (VIC)
- Murdoch Children’s Research Institute (VIC)
- Princess Margaret Hospital (WA)
- Queensland Children’s Medical Research Institute (QLD)
- Royal Children’s Hospital Brisbane (QLD)
- Royal Children’s Hospital Melbourne (VIC)
- Royal Perth Hospital (WA)
- School of Psychology (VIC)
- Sir Charles Gairdner Hospital (WA)
- The University of Queensland (QLD)
- The University of Sydney (NSW)
- University of Adelaide (SA)
- University of Melbourne (VIC)
- University of Queensland (QLD)
- University of Western Australia (WA)
- Walter and Eliza Hall Institute of Medical Research (VIC)
- Western Australian Institute of Medical Research (WA)
- Westmead Hospital (NSW)
- Womens and Children’s Hospital (SA)

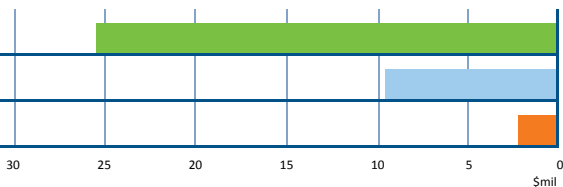


# 2012 - THE YEAR IN BRIEF

INCOME	Amount	%
Australian competitive grants	8,283,694	22.1
International competitive grants	1,047,420	2.8
Other competitive grants	1,424,150	3.8
Government contracts	5,517,653	14.7
Commercial income	4,569,490	12.2
Other grants	3,350,482	9.0
Miscellaneous income	517,277	1.4
Donations, fundraising & bequests	7,772,605	20.8
Investment income	1,889,654	5.1
Realised gain on investments	259,769	0.7
Research support	2,785,528	7.4
<b>Subtotal</b>	<b>37,417,722</b>	<b>100</b>
Deferred income adjustment	340,142	
<b>Total income</b>	<b>37,757,864</b>	



EXPENSES	Amount	%
Scientific research	25,119,096	67.9
Research administration and building services	9,559,435	25.9
Depreciation and provisions	2,302,276	6.2
<b>Total expenses</b>	<b>36,980,807</b>	<b>100</b>



**PROFIT** 777,057

## Staff and students

Total number of staff as at December 31 (paid and seconded) - 358

Total number of postgraduate students during the year - 96

Total staff and students in 2012 - 454

Total number of honorary and visiting scientists during the year - 140

# RESEARCH INCOME

## AUSTRALIAN COMPETITIVE GRANTS

Australian Research Council	405,305
Australian Rotary Health Research Fund	81,188
Juvenile Diabetes Research Foundation	116,976
National Health and Medical Research Council	7,513,057
National Heart Foundation Australia	167,168

## INTERNATIONAL COMPETITIVE GRANTS

Autism Speaks Inc	18,355
British Heart Foundation	33,323
Cystic Fibrosis Foundation Therapeutics	34,653
International Rett Syndrome Association	55,778
Juvenile Diabetes Research Foundation International	533,420
Miscellaneous Overseas Grants	9,519
National Institutes of Health	356,484
Wellcome Trust UK	5,888

## OTHER COMPETITIVE GRANTS

Asthma Foundation of Western Australia	35,619
Brightspark Foundation	129,463
Cancer Council of Western Australia	124,448
Children's Leukaemia and Cancer Research Foundation	668,861
Diabetes Research Foundation of Western Australia	75,000
Financial Markets Foundation for Children	57,169
Foundation for Alcohol Research and Education	79,977
Healthway	95,906
Heart and Lung Transplant Foundation	61,460
Melbourne Health	14,247
Raine Foundation	82,000

## GOVERNMENT CONTRACTS

Western Australia	
Department of Commerce	365,731
Department of Health	1,651,959
Disability Services Commission	49,350
Mental Health Commission	50,000
Federal	
Australian Agency for International Development	102,850
Cancer Australia	44,616
Department of Education, Employment and Workplace Relations	450,620
Department of Health and Ageing	1,731,295
Department of Innovation, Industry, Science and Research	672,796
Other	
Department of Education and Children's Services, South Australia	393,697
Miscellaneous - Non-WA State Governments	4,739

**5,517,653**

## COMMERCIAL INCOME

ALK Abelo A/S	167,500
Apache Energy Limited	75,000
Baxter Healthcare Pty Ltd	35,000
CSL Limited	5,756
GlaxoSmithKline Australia Pty Ltd	125,187
GlaxoSmithKline Biologicals SA	2,346
INC Research Australia Pty Ltd	234,073
Ipsen Pty Ltd	20,000
Johnson & Johnson Pharmaceutical Research & Development	29,073
MedImmune Inc	348,000
Novartis Vaccines and Diagnostics Pty Ltd	20,379
Novo Nordisk Pharmaceuticals Pty Ltd	80,000
Pfizer Pty Ltd	94,800
Phylogica Limited	2,879,689
Pilbara Iron Company (Services) Pty Ltd	249,935
PPD Australia Pty Ltd	7,667
Sanofi Aventis Australia Pty Ltd	90,000
Sanofi Pasteur	105,085

**4,569,490**

## OTHER GRANTS

Australian Research Alliance for Children and Youth	5,000
Autism Queensland Inc	35,000
Children's Cancer Institute Australia for Medical Research	15,000
Confederation of Meningitis Organisations (CoMO)	218,199
Curtin University	50,076
Edith Cowan University	1,000
Friends of the Institute for Child Health Research	50,182
King Edward Memorial Hospital	19,926
Lions Eye Institute	10,000
Miscellaneous	9,050
Papua New Guinea Institute of Medical Research	18,980
Princess Margaret Hospital for Children	544,179
Rebecca L Cooper Medical Research Foundation	19,200
Ruah Community Services	33,909
The Children's Hospital at Westmead	51,656
The George Institute for Global Health	129,850
Thoracic Society of Australia & New Zealand	21,140
True Blue Dreaming	30,000
University of Cambridge	34,297
University of Queensland	168,284
University of Western Australia	1,804,098
West Australian Sleep Disorders Research Institute	30,000
Western Australian Nurses Memorial Charitable Trust	20,000
World Heart Federation	31,456

**3,350,482**

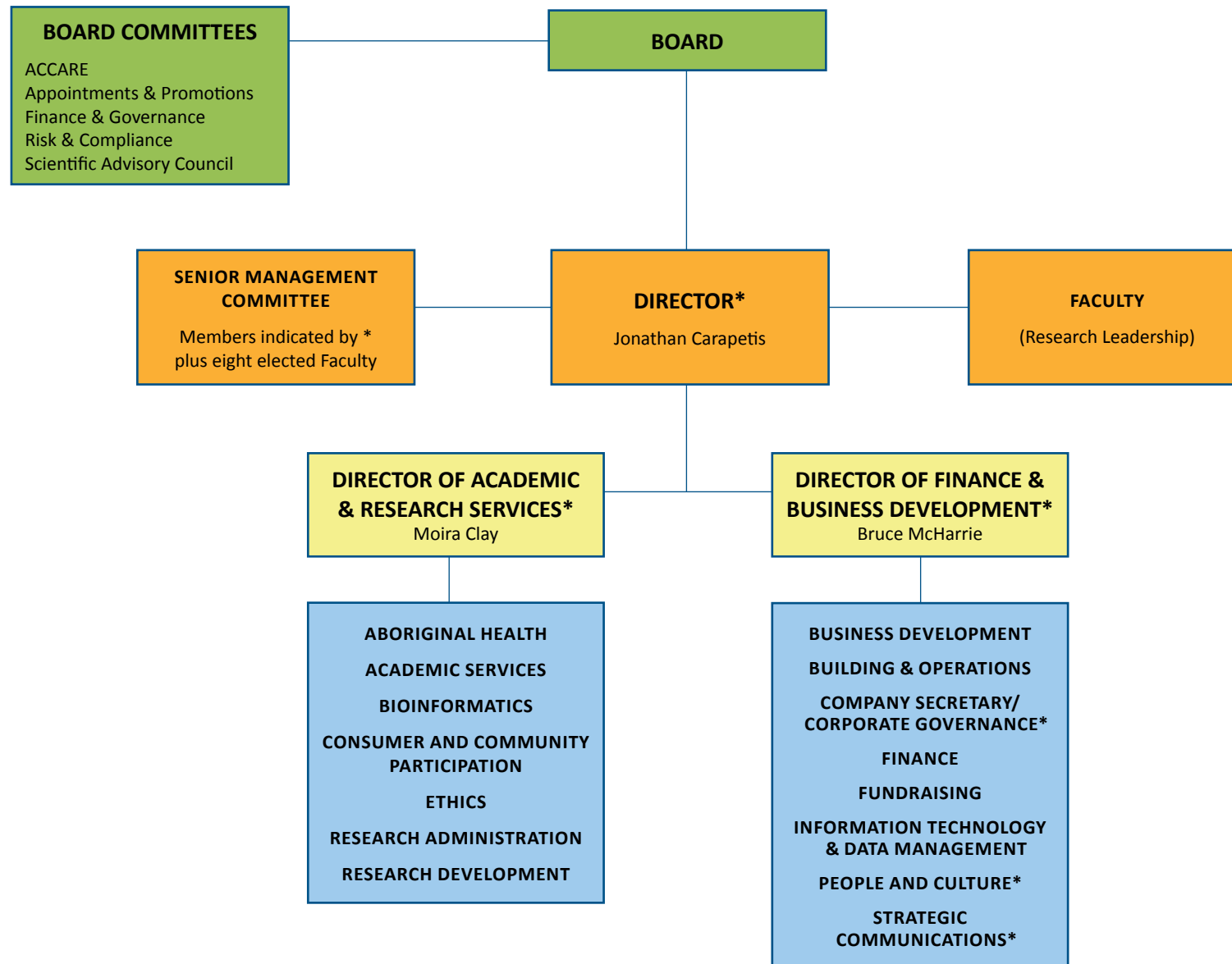
Miscellaneous income	517,277
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## TOTAL

**24,710,166**



# GOVERNANCE/MANAGEMENT STRUCTURE





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