

ANNUAL REPORT 2009



PREVENTION
INNOVATION
DEDICATION

Celebrating 20 years
1990 - 2010



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Telethon Institute for Child Health Research

What do you do when a child falls seriously ill, or suffers from a chronic disease or disability?

What do you do when you discover that a child is affected by a disorder like autism, or that they battle with anxiety or depression?

Many of us start asking questions.

What's the best treatment? Is there a cure?

Could it have been prevented? Why did this happen to my child?

For the past 20 years, scientists at the Telethon Institute for Child Health Research have been working to answer those questions that matter most to families.

Under the leadership of Professor Fiona Stanley, we pioneered an innovative approach that has brought together the best scientists from a wide range of scientific expertise to tackle these big issues from multiple angles.

It's an approach that has brought significant success in areas such as preventing birth defects, infectious diseases, childhood cancer and leukaemia, child development, disability, mental health and the issues facing Aboriginal children and their families.

Based in a purpose-built facility on the edge of the Perth CBD, the Institute has nearly 500 staff and post-graduate students focussed on improving the health and wellbeing of children. We also host around 80 honorary and visiting researchers throughout the year.

The Institute is an independent, not-for-profit organisation with strong affiliations with Western Australia's children's hospital and all the major universities.

Our mission

To improve and to promote the health and wellbeing of all children through the unique application of multidisciplinary research.

Our aims

- To conduct high quality research.
- To apply research findings to improve the health of children, adolescents and families.
- To teach the next generation of health researchers.
- To be an advocate for research and for children.



Director's Report



When we opened our fledgling research institute in 1990, there were many who thought we would not succeed. How could we build and sustain an internationally competitive centre of research excellence in an isolated city like Perth?

Twenty years on, we've come a long way. With nearly 500 staff and students and an abundance of visiting researchers, I am proud that the Institute has established a strong reputation and a track record of delivering real improvements in child health and wellbeing.

That certainly is demonstrated by the introduction in 2009 of mandatory fortification of bread-making flour with folate. Our research in the early days of the Institute helped prove the vitamin's role in reducing neural tube defects like spina bifida, but it's been our ongoing studies and advocacy that have finally pushed this important public health initiative over the line. Every year, dozens of babies will now be born healthy that might otherwise have suffered a significant disability – we'll never know who they are or which families have been spared the anguish, but the community as a whole should celebrate how medical research can sometimes offer quite simple solutions.

Looking back over the 20 years, there are many successes.

The Institute has been a powerful voice in providing the evidence and the advocacy that resulted in babies being immunised against a number of potentially devastating strains of meningitis. Our researchers have changed international thinking on the causes of childhood asthma. We've made important in-roads in identifying young cancer patients that are at higher risk of relapse. We've made important findings in the area of nutrition and mental health, as well as suicide prevention. Our research has shown that

there are multiple causes of cerebral palsy that occur before birth, and we've isolated the allergens that make dust mites and cats such a common problem for allergy sufferers. We can also lay claim to influencing government action on swimming pool fencing, bike helmets, SIDS campaigns and early education. Institute researchers also undertook the most comprehensive survey of Aboriginal child health and wellbeing – a massive exercise that produced four volumes of findings and recommendations that, if implemented, would significantly close the gap in outcomes for Aboriginal children and their families.

While celebrating our first 20 years, my real excitement comes from projecting what might constitute the next two decades of research and ensuring that the Institute is well positioned to embrace emerging challenges. For example, what will be the impact of climate change on the most vulnerable – our children? How will their mental and physical health be affected by changing nutrition, patterns of infectious disease, increased environmental and social stresses? If we look at how society has changed over the past 20 years and the impact that has had on children, we must anticipate significant challenges ahead.

So how do we respond? The advantage we have is our holistic approach to child health and wellbeing and our broad range of scientific expertise. We have been committed since inception to a multidisciplinary approach that brings together researchers with diverse scientific interests ranging from genetics, to biology, psychology, social science and epidemiology. This is particularly apparent in our research programs in children's cancer, asthma and infectious diseases, but is applied in the majority of our projects. This collaborative, multifaceted approach ensures we are broadly scanning the landscape in child health and wellbeing and well-positioned to both identify issues and respond. We also have the advantage of our fantastic data capacity built up over the last 20

years and top class researchers. It is crucial for us to continue to attract such people here to Western Australia.

In order to further capitalise on this multidisciplinary approach, we have recently undertaken a strategic review of the Institute's structure. As a result, we will move to an organisational structure based around disease/disability/issue groupings, rather than scientific divisions. For example, there will be research themes such as asthma, nutrition, infectious diseases, disability and Aboriginal child health that will include clinicians, basic scientists and those from the population health areas. This structure will have the added benefits of clarifying and creating career paths and opportunities for researchers and see a more direct translation of research into practice and policy.

It is, of course, very important that we continue to engage at the national and international level. I have been very pleased to continue to serve on the Prime Minister's Science, Engineering and Innovation Council, the Australian Social Inclusion Board and the State Government's Indigenous Implementation Board. In the past year, I also presented at the OECD World Forum on Statistics, Knowledge and Policy in South Korea, the International Society of Child Indicators in Sydney and attended the Global Forum for Health *'Innovating for the health of all'* in Havana, Cuba. My international speaking engagements have also taken me to Canada, North America, the UK and New Zealand.

Our future has also been boosted with our researchers being awarded a \$9.7 million grant from the National Health and Medical Research Council to undertake a five year program of work that looks at the social, economic and environmental factors in early life that have long-term impacts on health and wellbeing. I was also very proud of the successful completion of the first Capacity Building Grant comprising solely of Aboriginal researchers.

After the retirement of Mr Bob Ginbey last year, we have welcomed Mr Sash Tomson to the Institute as the new Chief Administrative Officer. Sash has extensive management experience, particularly in the Government sector, and is already proving to be a wonderful asset to the Institute. At the end of the year we farewelled with our best wishes our Director of Academic and Research Services, Professor Mike Garlepp. After a long and productive relationship, we also said goodbye to Professor Sven Silburn as he moved to the Northern Territory. I am pleased to say that we have retained a number of collaborations with Sven and he will remain a regular visitor. Likewise, while our long-time head of Clinical Sciences, Professor Peter Sly, has taken up a new position in Queensland, we continue to enjoy his continued involvement in a number of innovative projects.

We remain indebted to the people of Western Australia who so willingly participate in and support our research projects. We are also very grateful for the ongoing financial support we receive through Channel 7's Telethon – a team that works so hard to help children throughout the State. We are very honoured to be a major beneficiary.

So, after 20 years we can confidently say that we have a firm foundation – a solid track record and a fabulous staff and Board, to whom I am extremely grateful for their ongoing efforts and enthusiasm. The challenge now is to build on that foundation to ensure that we continue to deliver on our mission to improve and promote the health and wellbeing of all children. Who can imagine what changes and discoveries the next 20 years will hold?



2009 Highlights



Our priority is to ensure translation of research into action that makes a real difference to the lives of children and families.

In 2009, Institute researchers were recognised for their research outputs, their high-level advocacy and their impact on policy.

Mandatory folate fortification win

The introduction of mandatory fortification of bread making flour with folate, approved by Food Standards Australia New Zealand (FSANZ), will help to save hundreds of families from the heartbreak of serious birth defects.

Professor Fiona Stanley and Professor Carol Bower are at the forefront of research in Australia into the role of folate in reducing neural tube defects. Their research indicates that mandatory fortification will reduce the incidence of spina bifida and other devastating neural tube defects.

Binge drinking leads to fetal risks

A study conducted by Institute researchers along with the National Perinatal Epidemiology Unit at the University of Oxford, investigated the relationship between prenatal exposure to alcohol and the adverse effects on fetal growth and pre-term birth. The study, published in *BJOG: An International Journal of Obstetrics and Gynaecology*, found heavy and binge levels of alcohol during pregnancy increases the risk to the baby, even if drinking is stopped in the first three months of pregnancy.

New meningococcal vaccine

Adolescents aged between 11 and 18 years took part in a meningococcal B vaccine trial that could potentially provide protection against the most common form of meningococcal disease in Western Australia. The research project was undertaken by the Vaccine Trials Group at the Institute and Princess Margaret Hospital for Children.



Dr Peter Richmond gives a meningococcal B vaccine to volunteer Sarah McGovern.

Rise in drug affected newborns

Institute researchers published a report on a study that found the number of newborns suffering serious drug withdrawal symptoms is now more than 40 times higher than in 1980. The research, published in the international journal *Pediatrics*, also found that these infants were at greater risk of neglect and of being taken into care. The study identified a range of factors that should assist with the early identification of children at risk.

Ground-breaking \$9.7 million grant for child health studies

Our researchers were awarded a prestigious \$9.7 million grant to undertake an unprecedented program of research to determine the critical social, economic and environmental factors in pregnancy and early childhood, that have a lifelong impact on health and wellbeing. The program grant from the National Health and Medical Research Council funds five years of research from 2010. The work will be undertaken at the Institute in collaboration with researchers from The University of Western Australia and Curtin University.

30 per cent of children at risk of future heart disease

The Medical Journal of Australia referred to Institute research when it reported that almost 30 per cent of 14-year-old Australian children fall within a group identified as being at future increased risk of heart disease, type 2 diabetes or stroke.

The study, conducted by a WA research team including Institute researchers, identified children at risk of future cardiovascular disease with features of metabolic syndrome.

NOMAD Two Worlds

The Institute became the global philanthropic partner of NOMAD Two Worlds, a unique collaboration in art and culture by international photographer Russell James and Aboriginal artist Clifton Bieundurry. The NOMAD Two Worlds project was launched in New York during G'Day USA Week and has since been exhibited at the National Gallery of Victoria and the Institute.

Professor Fiona Stanley also featured in an inspiring video on the Apology to the Stolen Generations by Will.I.Am (Black Eyed Peas and responsible for the Barack Obama "Yes We Can" video) and Russell James.



Russell James, Fiona Stanley and Clifton Bieundurry.

Quitting smoking in pregnancy a good sign for child behaviour

Our researchers have shown long term benefits for a child if their mother quits smoking even after the pregnancy is established.

The findings, published in the *Journal of Epidemiology and Community Health*, revealed that even if a woman is still smoking in the first few months of pregnancy, it is not too late to quit to improve the outcomes for her child.

The study also showed that smoking throughout pregnancy results in a much higher risk for behavioural problems in children than those children whose mothers did not smoke, or quit smoking before four months gestation.



Photo courtesy The West Australian

Language development

Looking at Language Principal Investigator, Professor Mabel Rice, from the University of Kansas, made a significant discovery with the identification of a candidate gene for Specific Language Impairment. Professor Rice, who visits Perth regularly, said the results point toward the likelihood of multiple genes contributing to language impairment, some of which also contribute to reading or speech impairment. Data from the Looking at Language Project will now be used to investigate these genes further.

2009 Highlights

Western diet linked to teen's poor mental health

An Institute research paper published online in the international journal *Preventive Medicine*, showed a link between Western-style diets and increased mental health problems in teenagers.

The results were based on detailed analysis of diet records and behaviour checklists collected from more than 1600 West Australian 14-year-olds in the Raine Cohort Study. The analysis found that higher levels of behaviour and emotional problems were associated with a more Western-style way of eating, namely a diet high in takeaway foods, red meat, confectionery, soft drinks, white bread and unrefined cereals.

Chemicals at work may lead to birth defects

Our researchers found a possible association between parental occupations and common birth defects, which warrants further investigation.

The research, published online in the international journal *Occupational and Environmental Medicine*, found that mothers who may be exposed to heavy metals in their occupations were two and a half times more likely to have a son diagnosed with hypospadias, a common birth defect that affects the penis. Study co-author Dr Natasha Nassar said the findings

were an important starting point, but the results were preliminary and are being further investigated in the Understanding Hypospadias Study.

School success starts before birth

An Institute research team revealed a link between healthy growth in the womb and improved numeracy and literacy skills in early primary school.

Published in the international *Journal of Epidemiology and Community Health* and *American Journal of Epidemiology*, the studies showed that healthy fetal growth not only helps to improve a child's performance at school, but that it may also contribute towards closing the achievement gap for children from disadvantaged socioeconomic backgrounds.

Study co-author Professor Fiona Stanley said the findings reinforce the need for better integration of health and education policies and services.

Insight into Rett Syndrome

A research collaboration between Australia and Israel identified a genetic variation that influences the severity of symptoms in Rett syndrome. The finding, published in the international journal *Neurology*, uncovered a potential new target for treatment of the debilitating neurological disorder.



Members of the Indigenous Capacity Building Grant.

Photo courtesy The West Australian.

Aboriginal researchers achieve milestone

The first Capacity Building Grant comprising solely of Indigenous researchers was completed successfully, generating a wide range of research and skills to improve the health and wellbeing of Aboriginal children and their families.

The five-year grant from the National Health and Medical Research Council (NHMRC) enabled 10 Aboriginal researchers to make significant contributions to dozens of reports, books, journal publications, international and national publications, competitive grant submissions, PhDs as well as secure two awards for NHMRC post-doctoral fellowships.

The researchers also took part in a National Roundtable on Research on Racism toward Indigenous Australians which led to a united Declaration on

racism and a submission to the Human Rights and Equal Opportunity Commission.

Better diagnosis leads to higher autism rates

An Institute research team found that the rapid increase in the number of children diagnosed with autism spectrum disorders (ASD) in Western Australia reflects changes to diagnostic practices and services.

The research, published in the *International Journal of Epidemiology*, investigated factors behind the concerning increase in autism rates.

The study also observed that children were being diagnosed at a younger age, reflecting better awareness and parents' willingness to access early intervention services.

Teen girls regret having sex earlier

A study by Institute researchers in partnership with UWA's School of Paediatrics and Child Health, has found that teenage girls who lose their virginity when they are not ready - often at an earlier age - are more likely to feel disappointed and regret the experience.

The research paper "Perceptions and experiences of first sexual intercourse in Australian adolescent females" was presented at the Paediatrics and Child Health Division of the Royal Australasian College of Physicians Conference in Sydney.

IVF twins have more health problems

Our researchers have found that twins born as a result of assisted reproductive technology (ART) such as IVF are more likely to be admitted to neonatal intensive care and to be hospitalised in their first three years of life than spontaneously conceived twins of unlike-sex.

Alcohol in pregnancy linked to child behaviour problems

An Institute research project found evidence that the amount and timing of alcohol consumption in pregnancy affects child behaviour in different ways. The study, published online in the international journal *Addiction*, suggests that both the timing and the intensity of alcohol exposure in the womb affect the type of behaviour problems expressed.

Jim McGinty joins Institute Board

Former WA Health Minister, the Hon Jim McGinty, was appointed to the Board of the Institute.

Institute Director, Professor Fiona Stanley, said Mr McGinty had shown a long-term interest in improving outcomes for children.

Mr McGinty said he had worked closely with Professor Stanley over many years and was very pleased to be invited to join the Institute Board.

Better management of rare conditions

Families and clinicians caring for girls with the rare and debilitating neurological condition Rett syndrome can now access a comprehensive guide to the best management of one of their most significant issues, scoliosis.

The booklet contains a set of guidelines based on the findings of a research paper that was published in the international journal *SPINE*. The guidelines were developed in response to limited professional literature about the clinical management of Rett syndrome.

Study opportunity for Aboriginal Health Workers

As part of the Rio Tinto Aboriginal Health Partnership: Strong Foundations, Sustainable Futures, a scholarship program offering Aboriginal Health Workers an opportunity to take up further study was launched.

First national snapshot of Australia's young children

Launched by Deputy Prime Minister, Julia Gillard and the Minister for Early Childhood Education, Child Care and Youth, Kate Ellis, the first national results from the Australian Early Development Index (AEDI) revealed that around two-

thirds of children are doing well in five key developmental areas.

The AEDI is conducted by the Centre for Community Child Health at The Royal Children's Hospital, Melbourne and the Murdoch Children's Research Institute, in partnership with the Institute.

The Institute's Professor Steve Zubrick said the AEDI had repeatedly proven its value since initial studies in WA in 2002, providing communities with a blueprint for action to ensure that young children get off to a solid start in life.

Shell Australia Chairman, Mr Russell Caplan, said the company was very proud to have supported the AEDI pilot project and the Indigenous Adaptation Study.

The Australian Government has committed \$21.9 million to implement the AEDI nationally.



Michele Hansen with IVF twins Amy and Joel.
Photo courtesy The West Australian.



Ministers Kate Ellis and Julia Gillard at the AEDI launch.

Nick Gottardo



What makes Dr Nick Gottardo so dedicated to his profession is his belief that it's unacceptable for children to die from brain tumours. Nick's exuberant urgency represents a man on a constant deadline, and with such important work to be done, it's no surprise.

Along with Dr Peter Dallas, Nick leads the Brain Tumour Program team in the Division of Children's Leukaemia and Cancer Research, headed by Professor Ursula Kees. The team's essential work is striving for a future where brain tumours are completely preventable and their causes well understood.

"In conjunction with Peter, I have two research projects investigating two different types of brain tumours: one is Ependymoma (the 3rd most common brain tumour) and the other is Medulloblastoma (the most common malignant brain tumour)," Nick explains.

"My area of expertise is developing mouse models of these diseases, in an effort to have models where we can test new therapies and try and identify areas of weaknesses in the tumour that might be suitable drug targets. With these models, we can then test new drugs or previously developed drugs which have never been used for these kinds of tumours."

Nick's medical career began at Leeds University with a Bachelor of Medicine, Bachelor of Surgery/Chirurgery. He worked for two and a half years as a doctor in the UK, before heading to Australia in 1996, for what was initially to be a 'working holiday.' He soon found himself settled in Perth, working for Princess Margaret Hospital for Children.

"It was during that time I did my PhD with Professor Kees, in T-cell acute lymphoblastic leukaemia," Nick says.

"During my PhD studies I conducted gene expression profiling studies, using a technology known as microarrays. I measured the level of activity (the expression) of thousands of genes at once, to obtain a global picture of the cellular function of leukaemia specimens."

While working with children with tumours, it became apparent to Nick that with leukaemia, research had really transformed a disease which 40 or 50 years ago was essentially fatal, where now up to 80 per cent of children are cured.

"The same cannot be said for brain tumours," acknowledges Nick.

"Many brain tumours remain incurable and the ones that we can cure, often leave the children with a lot of long-term side effects, as a result of current therapies. So, childhood brain tumours appeared to me to be an under-researched area and one in which I could make a difference, if I was equipped with the necessary skills."

In searching the world for places to train, Nick settled on St Jude Children's Research Hospital in Memphis, Tennessee, one of the world's premier childhood cancer institutes. He spent three years at St Jude and gained additional experience in the lab as a post-doctoral brain tumour fellow as well as experience in the clinic.

"My aim was to come back to Perth as a dual trained clinician/scientist," Nick explained. "To be able to not only look after the children, but also use the knowledge I have in the clinical setting to finding new therapies or new ways of trying to cure children with brain tumours."

"I treat all childhood cancers, but really it's brain tumours that I want to make a difference in."

Nick discovered fantastic opportunities at St Jude, both in terms of research project options and his clinical mentor Amar Gajjar, who is now the chair of the Brain Tumour Committee at the international Children's Oncology Group.

"When I arrived in Memphis, my research boss Dr Richard Gilbertson - an incredible person and a recognised world leader in childhood brain tumour research - offered me numerous projects that I could work on and I chose one of the riskier ones," Nick says. "My aim was to develop a mouse model of Ependymoma, which had never been done before. So I genetically engineered a mouse and eventually the mice developed these tumours, so it was a completely new discovery."

Nick joined the Institute on his return from the United States in August 2008, having created a mouse from scratch that actually develops Ependymomas. This was the project he brought with him to the Institute to try and develop further, as a model to test new therapies.

Funding from the Lillee Bequest Fellowship allowed Nick to establish his lab on his return to Perth.

"Without start-up funds I would not have been able to

continue my brain tumour research in Perth - it was really nice that I was given this chance," Nick says. "Ultimately, all research boils down to funding. You may have great ideas and be well-trained, but if you don't have some money to back you up, well..."

Nick says the Lillie Bequest Fellowship was instrumental in allowing him to return to Perth and establish his lab. "Essentially I came into a ready-established lab and was able to establish my own small lab within the bigger infrastructure."

From his time in the United States, Nick has seen the benefits of adequate funding first hand.

"A very wealthy gentleman donated around USD\$12m to our lab at St Jude to research one specific tumour. It's not often someone comes along and says 'Here's \$12 million, go and find a cure for this disease.' I'm not sure why we don't have that in Australia, given this is such a wealthy country and we're now one of the strongest economies, as shown by the recent global financial crisis," Nick explains.

"The hospital where I trained never charged the patient, which is quite unique in America. It was irrelevant whether you were the son of a millionaire or the son of a pauper, you got the same treatment and the same standard of care.

"To me, St Jude is a utopia of medical practice and research, a place where researchers and clinicians all work together with the common goal of curing childhood cancer. St Jude strives to attract the best researchers and clinicians from around the world. They provide generous start-up funds and facilities for five years in order for you to establish your research laboratory. They allow you that period of time to establish yourself and get some publications, which ultimately is how success is measured in research. After that period you are expected to attract your own funding - I think this approach is very fair and a good model," he says.

Nick explains the most difficult thing about research is constantly having to write grant proposals in order to try to obtain the funding to continue your research.

"I do tend to get frustrated, constantly writing about what I want to do and what I'm going to do, instead of getting out there and doing it," Nick says. "I think it would be nice

if there was more extensive and easier-to-obtain funding, especially for early career scientists who are trying to establish themselves. Obviously it needs to be peer-reviewed because you do not want to pour money into poorly thought-out research projects, but the current funding environment is so highly competitive that funding is very hard to obtain, and this can be quite demoralising," Nick admits.

A Fellow of the Royal Australasian College of Physicians, Nick is so inspired by the advances his predecessors made with similarly once fatal conditions such as leukaemia; he believes the same can be achieved with brain tumours.

"Working with children with brain tumours is not easy," Nick admits. "It is devastating when one of your patients dies or is severely affected in the long term by their illness and treatment. That is what drives me - the belief that we can improve on the current situation.

"If you came through the doors of PMH in the 70's or early 80's you would have most probably died from leukaemia. You come through the doors now and you've got an 80 per cent chance of being cured.

"That's because somebody visionary at the time said this is not acceptable, we need to do something and not accept that these children are going to die".

Nick believes we are now at the dawn of a new age of therapies for cancer.

"We have entered a new era of molecular targeted therapies - or 'silver bullets' if you like - where we try and target weaknesses or the Achilles heel in the cancer by specifically blocking a molecule or molecules that the cancer needs to grow and survive. There is great hope that these



Dr Nick Gottardo with Tom Keenan.

therapies might improve the outcomes for children with brain tumours."

When Nick is not at work, he tries to spend as much time as he can with his family.

"I have a 6-year-old daughter and a 12-week-old son, and at the moment I try and spend as much time as I can with them and my wife so that they get to know who their father and husband is," Nick says.

Although in possession of a black belt in Tai Kwon Do, Nick admits this interest has dropped by the wayside, with such an enormous amount of work still to be done.

"My aims are to take discoveries from the lab into the clinic. If I can make a discovery that can be translated into a new therapy for children with brain tumours, that would be my ultimate goal. That's the kind of contribution I would like to make to the field."

Chairman's message

As the Institute celebrates 20 years of success, it's timely to also look forward to what the next 20 years might bring. As one would expect, planning for the future has been a critical part of considerations by the Board over the past year.

That forward planning has included preparing for a range of scenarios such as our capacity to respond to emerging diseases and issues and succession planning. However, underpinning our strategies to address these priorities is our ability to ensure sustainable funding into the future.

There are a number of elements to this. Fundamentally, our research is funded by competitive grants and that requires ensuring that we recruit and retain scientists who are well-respected and productive within their fields. The Board's commitment to this has been demonstrated by our salary parity initiative which aims to close the gap between Institute and university pay scales within the next few years.

However, the grants do not cover the full cost of research, nor do they allow us to provide the carrots required for strategic recruitment. Funding for research support and infrastructure is, in our view, predominantly a State and Federal Government issue. We are disappointed that the State Government's Medical Health and Research Infrastructure Fund (MHRIF) remains capped at \$5 million for the fifth year in a row. There has been a significant increase in the number of competitive research grants that our scientists have won over the same time. Consequently, the MHRIF funding rate has declined from a high of 36.8 cents per research dollar in 2002 to the current level of 16 cents.

An independent review has demonstrated that the average cost of research support is 60 cents in the dollar. While the Federal Government has agreed to fund Universities for indirect costs at 60 cents per dollar of competitive research funding by 2014, medical research institutes receive on average 30 cents per research dollar, when combining both Federal and State Government funding for indirect costs. This means that not only are we being penalised for our increased success, we are forced to fund the difference between actual costs and State and Federal income from commercial contracts, government contracts and donations. The impact of this is that we're not able to deploy all our strategic reserves towards frontline research activities or strategic recruitment and retention of our rising stars and research leaders.

Another crucial element of our financial planning is the Institute's ability to elicit support from the philanthropic and corporate sector. There is no doubt that the global financial crisis had a significant effect on philanthropy. It is in this climate that we remain particularly grateful for the ongoing support from Channel 7's Telethon and Australian Capital Equity. The recent global financial crisis has also resulted in a fall in investment income used for strategic and research support purposes. This has meant that the Institute has had to dip even further into its reserves to support everyday operations. This situation is unsustainable in the long-term and reinforces the importance of achieving full funding for the cost of the research from State and Federal Governments.

Planning continues for the Institute to relocate to the Queen Elizabeth II site along with the State's children's hospital. We see the potential move as presenting an exciting opportunity to boost the translation of our research from the bench to the bedside with the physical proximity and new design enhancing research, training and education links. We have some funds committed from the State and Federal Governments but these are insufficient to enable the move at this stage. We continue to pursue further funding through a range of government and non-government avenues.

In what has been a busy year, I would like to thank the Board for their ongoing support and commitment. I would particularly like to acknowledge Keith Jones who stepped down from the Board after nine years of service. We also farewell Professor Jackie Huggins who made a significant contribution, albeit from a distance in Queensland.

I am very pleased to welcome some new faces, talent and experience to our group in former WA Health Minister Hon. Jim McGinty, the Dean of Health Sciences at Murdoch University Professor Rhonda Marriott, UWA Emeritus Professor Margaret Seares and Ernst & Young Managing Partner Mr Jeff Dowling.

Finally I commend Professor Fiona Stanley for her outstanding leadership of the Institute over the past 20 years. Even with her enviable vision and enthusiasm, I doubt that she would have foreseen the size and scope of the impact the Institute has already had in improving health and wellbeing of children and families.

John Langoulant
Chairman

Board of Directors

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



John Langoulant, Chair, Telethon Institute for Child Health Research; Chief Executive Officer, Oakajee Port and Rail; Member, Senate of The University of Western Australia; Board Member, Western Australian Ballet; Board Member, Committee for Perth; Board Member, Council of Australian Governments (COAG) Reform Council.

Jeff Dowling, Managing Partner, Ernst & Young Western Region; Member, Australian Institute of Company Directors; Member, Institute of Chartered Accountants Australia; Associate Member, Financial Services Institute of Australasia; Member, National Management Committee for Ernst & Young; Member of Board of Trustees, United Way.

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



Jenni Ker, President, Friends of the Institute.

Michael Manford, Executive Chairman, Patersons Securities Limited; Board Member, Australian Business Arts Foundation; Councillor, St Hilda's Anglican School for Girls.

Rhonda Marriott, Faculty Dean of Health Sciences, Murdoch University; Chair, Aboriginal Collaboration Committee for Applied Research and Evaluation; Board Member, Public Health Advocacy Institute of Western Australia.



Jim McGinty, Chairman, Health Workforce Australia; Chair, Curtin University Medical School Steering Committee; Former WA State Health Minister; Former WA Attorney General.

Margaret Seares AO, Former Senior Deputy Vice-Chancellor, The University of Western Australia; Board Member, West Australian Symphony Orchestra; Board Member, Perth International Arts Festival; Board Member, The Creative Industries Innovation Centre; Board Member, Centre for Creative Industries; Board Member, Education Investment Fund; Board Member, National Research Infrastructure Council; Fellow, Australian Institute of Company Directors.

Fiona Stanley AC, Director, Telethon Institute for Child Health Research; Chair, Australian Research Alliance for Children and Youth; Professor, School of Paediatrics and Child Health, The University of Western Australia; Member, Prime Minister's Science, Engineering and Innovation Council; Member, Australian Social Inclusion Board; Member, WA State Government Indigenous Implementation Board; Australian of the Year 2003.

Retired in 2009 and not pictured: Keith Jones, Jackie Huggins, Louis Landau.



*“Somewhere,
something
incredible is
waiting to be
known.”*

Dr Carl Sagan

At the Telethon Institute for Child Health Research, nearly 500 staff and post-graduate students share a dedication to improving the health and wellbeing of children and their families.

Our research is focussed around eight major streams:

- Aboriginal child health*
- Asthma, allergy and respiratory disease*
- Children's cancers*
- Healthy development*
- Infectious disease*
- Social and emotional wellbeing*
- The early years*
- Understanding disability.*

Our priority in every area is on prevention – of disease, disability and disadvantage.

*In the following pages we provide a snapshot of some of the major projects and studies being undertaken at the Institute. **Full reports for all projects can be found on our website -***

www.childhealthresearch.com.au



A close-up portrait of an Aboriginal child with dark, curly hair and large, dark eyes. The child is wearing a red t-shirt with a grey collar. The background is blurred, showing green foliage.

ABORIGINAL CHILD HEALTH

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

The Institute's ground-breaking Western Australian Aboriginal Child Health Survey remains the most comprehensive analysis ever undertaken of these issues. Four volumes of findings and comprehensive recommendations have been published relating to health, social and emotional wellbeing, education, family and community.

Staying on Track: Reducing Substance Misuse for Aboriginal Young People in Port Hedland and Newman

This project is funded through the BHP Billiton Iron Ore Health Partnership and looks at identifying and developing innovative preventative programs to address issues of substance use in Newman, Hedland and surrounding communities.

A range of activities were conducted during the life of the project which focussed on physical wellbeing, safe talk, enhanced self esteem, positive messages, skills development, and reducing boredom. Programs were aimed at young people up to 25 years of age and included:

- Hip hop workshops for 12- 25 year olds
- The drug, alcohol and smoke-free Port Bound Festival which promoted positive youth and health messages and provided useful information, resources and links to relevant services for young people
- The Hedland Youth Directory focussing on physical safety and wellbeing, empowerment and social involvement, interaction with stakeholders and access to information on services and resources
- The Hedland Youth Leadership Council, promotes notions of ambassadorship and positive role models through a range of leadership programs, youth groups in Hedland, Newman and surrounding communities
- The Swim for Life program supports and promotes the aspirations of young people and focuses on developing skills, esteem and achievement.

Not Just Scholars But Leaders: Learning Circles in Indigenous Health Research

2009 was the final year of a five-year grant from the National Health and Medical Research Council which looked at mental health, self-esteem, transition zones for young Nyungar males, gender issues, substance abuse, bullying, juvenile justice, primary health care, and human rights.

The first Capacity Building Grant comprising solely of Indigenous researchers was spearheaded by the Telethon Institute, along with Curtin University, the University of Western Australia and the Combined Universities Centre for Rural Health.

During the grant, the 10 Aboriginal researchers contributed to 14 substantial reports, nine books/or chapters in books, 35 journal publications, 32 presentations at international conferences, 37 presentations at national conferences and 48 competitive grants. Five have enrolled in PhDs, two have been completed, one with distinction. Two researchers have been awarded prestigious National Health & Medical Research Council post-doctoral fellowships.

Rio Tinto Aboriginal Health Partnership – Strong Foundations, Sustainable Futures

This Partnership aims to bring about improvements in the area of Aboriginal child and maternal health by addressing some of the training, development and support needs of Aboriginal Health Workers in the East Kimberley, Pilbara, and South Metropolitan area of Perth.

During 2009, the *Start Stronger, Live Longer*

health resource for Aboriginal Health Workers was developed. This resource emphasises the importance of a good start in life and focuses on seven key themes including nutrition, smoking and mental health as well as maternal, infant, child and adolescent health. Workshop training to demonstrate the use of the resource will take place across the State in 2010 along with a national symposium focussing on the seven themes.

In 2009, two scholarships were awarded through the partnership - Lyn Cheedy completed her diploma in Aboriginal Health Work, graduating top of her class from Marr Mooditj Aboriginal Health Training College and Sarina Morgan who will complete her studies with Kimberley Aboriginal Medical Services School of Health Studies in 2010.

The Rio Tinto Aboriginal Health Partnership is a collaboration between Rio Tinto and the Institute through our Kulunga Research Network.

Awareness and impact of the ‘Make Smoking History’ advertising campaign among Aboriginal smokers in Western Australia

Anti-smoking mass-media campaigns have been shown to reduce smoking prevalence in the mainstream community. It is unclear, however, if these campaigns have any affect on Aboriginal smokers.

We asked participants from metro Perth, Broome and Kalgoorlie about their awareness of the advertisements in the campaign, whether they found them believable and relevant, and the impact the advertisements had on their smoking behaviour.

The majority of the participants interviewed had seen the television advertisement (which had greater awareness) and/or heard the radio advertisement. Both forms of advertising were considered to be believable and relevant by the majority of Aboriginal smokers. Most of the smokers interviewed thought about cutting down and/or quitting after seeing or hearing the advertisements, however very few had successfully quit in the two months prior to the study interview.

More needs to be known about what motivates Aboriginal smokers to quit, or to not smoke at all. A better understanding of these motivations may lead to more effective cessation interventions and mass-media campaigns.

Maternal and Child Health Models of Excellence Project

This project involves working in partnership with the Aboriginal Health Council of Western Australia to build sustainable gains in the quality of maternal and child health through the establishment of Models of Excellence in selected Aboriginal Community Controlled Health Services (ACCHS) in Western Australia.

The project operates in three service sites - Geraldton Regional Aboriginal Medical Service, Mawarnkarra Health Service in Roebourne and the Ord Valley Aboriginal Health Service in Kununurra. In addition to the work undertaken in these sites, an audit and needs assessment of maternal and child health services provided by the ACCHS has been completed and will form the basis of future work to continue to build on the quality of maternal and child health through this sector.

ASTHMA, ALLERGY & RESPIRATORY DISEASE



Asthma is a highly complex disease and has been increasing in the western world in recent decades. In Australia, more than two million people suffer with this chronic condition.

For the past 15 years, our world-leading scientists have been tracking the early pathways that lead to asthma and allergy.

The Institute also runs a major research program in cystic fibrosis which affects about one in every 2000 babies born in Australia. Our investigations are focussed on preventing early lung damage.

Cystic fibrosis

Australian Respiratory Early Surveillance Team for Cystic Fibrosis (AREST CF) is a collaboration of specialist paediatric cystic fibrosis centres in Perth and Melbourne and consists of over 25 doctors, researchers and scientists dedicated to the improvement of respiratory health and outcomes in children with cystic fibrosis. Our Early Surveillance Program focuses on the assessment, treatment and prevention of cystic fibrosis lung disease in children and is specifically aimed at children under the age of seven years.

AREST CF has continued to provide new data on the early course of lung disease in babies and young children with cystic fibrosis. The data gathered by the early surveillance program have been used to propose a new clinical trial designed to prevent the onset of bronchiectasis in infants with cystic fibrosis.

Childhood asthma study

The Childhood Asthma Study has been following a group of 263 children at high genetic risk of developing asthma and atopy. They were recruited between 1996 and 1998. The children were followed closely for the first five years and extensive information on early respiratory infections, development of allergic diseases such as eczema and asthma, as well as wheeze was collected. We reported rhinoviruses, which were previously thought to be responsible for only mild cold symptoms, to be significant respiratory pathogens and responsible for three times the number of lower respiratory tract illnesses compared to Respiratory Syncytial Viruses. We also reported that in children who were sensitised early in life, that is by the age of two years,

the occurrence of wheezy lower respiratory illnesses were significant risk factors to the subsequent development of persistent wheeze at five years of age. We found no associations between antibiotic use and eczema, current wheeze, current asthma, atopic asthma, allergic rhinoconjunctivitis or atopy at five years of age. Any associations were due to reverse causation, in that children with these conditions were more likely to be in receipt of antibiotic treatment. Preliminary analysis of the 10-year follow-up data has found that the occurrence of fever during respiratory illnesses in the first year of life is an important marker of persistent wheeze and asthma, suggesting it should be considered as a risk factor in prospective studies of asthma aetiology.

Children's environmental health

The Institute's Division of Clinical Sciences was designated as a World Health Organization Collaborating Centre for Research on Children's Environmental Health in July 2006. The Centre is conducting high quality research aimed at understanding the mechanisms underlying the development of diseases of environmental origin in children, with special emphasis on respiratory disease such as respiratory infections, asthma and allergies. In line with the Centre's aim to build research capacity in developing nations, in 2009 we conducted a training workshop in Nanning in China to teach environmental scientists and medical doctors how to appropriately measure lung function and carry out neurodevelopmental assessments.

During 2009, we carried out an independent study of respiratory health and the association with air quality in the Kwinana region, south

of Perth. The Kwinana Children's Respiratory Health Study collected information on respiratory history and environmental data for almost 600 children. We also collected respiratory data using lung function techniques and allergy data through skin prick tests. The Department of Environment and Conservation has been monitoring the air quality around Kwinana and a six-month follow-up health and housing questionnaire will be completed by parents in 2010. The analysis will include comparing the results to similar studies around Australia, to see if variations in lung function, air quality and other risk factors related to respiratory health can be identified. The study was commissioned by the WA Department of Health and is guided by a steering group with representatives from the community and industry as well as local and state government.

Asthma and UV

With the incidence of allergies and asthma increasing in both Australia and worldwide, new and novel ways to prevent and dampen existing disease must be considered. We have shown that exposure of the shaved skin of mice to UV rays, similar to those found in sunlight, can reduce the development of asthma disease. Our research is focussing on how the UV light is working and what molecules are induced in skin to reduce the incidence and severity of the disease in the lungs. One candidate molecule produced in skin exposed to sunlight is vitamin D. We know vitamin D is important immunologically but we are investigating its importance relative to other molecules produced in UV-irradiated skin. A better understanding will hopefully lead to new approaches for prevention and treatment of allergies and asthma.

Allergy

Allergy is defined as the inappropriate or exaggerated response of the immune system to harmless stimuli in the environment. Australia has one of the highest rates of allergy and asthma in the developed world. Allergy to house dust mite and cat allergens are the major causes of allergy in Australia.

Our Molecular Biotechnology laboratory has previously identified the important mite allergens to improve immunotherapy for allergy sufferers. In 2009, we discovered two novel cat allergens that are the most significant allergens for a large number of cat-allergic people. A major focus of our recent research is to produce a range of rhinovirus proteins to measure anti-rhinovirus immune responses. A new type of rhinovirus (type C) was identified in 2007 that appears to be associated with more severe asthma and respiratory disease. There are limited reagents for measuring anti-rhinovirus immune responses and none are available for the type C rhinovirus.

Global prevention of asthma in children

Asthma is the most common chronic illness in children and there is no current way of preventing the development of asthma. We have been leading a world-first international trial of an asthma vaccine. The study involves giving children drops under the tongue of a mixture of the three most important allergens associated with asthma - house dust mite, grass and cat. Over 15,000 doses of allergen or placebo have been given to 150 children without any treatment-related serious adverse events. This first cohort of children has finished treatment and the follow-up phase will be completed during 2010.

CANCER



Researchers at the Institute are looking at both genetic and environmental clues to what causes Acute Lymphoblastic Leukaemia (ALL). And, while more than 80 per cent of children recover from the disease, we have found important genetic markers that help to explain why some children don't respond well to therapy. It's an important step in developing more targeted treatments.

Our researchers are also investigating primitive neuroectodermal tumours, the most common type of brain tumours affecting children. Survival rates have remained in the 50 to 70 per cent range for the past 20 years. Many survivors face long-term effects as a result of brain surgery and chemotherapy or radiotherapy.

Leukaemia

Every year in Western Australia, 60 to 70 children are diagnosed with cancer and almost half of these have leukaemia.

Leukaemia is the most common cancer in children, affecting around one in every 2000 Australian children. Cancers in children vary greatly from cancers in adults - the types of tissues affected are different and children seem to get cancers for different reasons, although the causes are still not fully understood.

Survival rates for children with leukaemia have reached around 80 per cent, a considerable improvement from the low rates of only a few decades ago. Despite these high cure rates, resistant forms of childhood leukaemia remain a leading cause of relapse, as well as cancer-related death, in children. These drug-resistant leukaemias don't respond as well to chemotherapy, which remains the best form of therapy for treating leukaemias, resulting in relapse and a return of the leukaemia.

Laboratory research

Our researchers have developed a specialised technique to 'grow' cancer cells in the laboratory so they can use them to find better treatments for leukaemia. These high quality cell lines retain many of the features of the primary disease, including similar growth rates, allowing researchers to accurately test new chemotherapy drugs. Our researchers have investigated several novel drug therapies which are being further investigated in our laboratory.

Our leukaemia laboratory also works very closely with oncologists at the Princess

Margaret Hospital for Children to predict relapse in patients so that therapies can be tailored to individual children to improve their long-term prognosis. For those patients who relapse, many develop resistance to chemotherapy drugs making a cure hard to achieve. It is still unclear how patients develop resistance and our research is trying to understand the genetic mechanisms underlying the development of drug resistance so we can develop novel drug targets.

Epidemiology research

Researchers have been analysing the five years of data collected for a national study looking into the causes of childhood acute lymphoblastic leukaemia (ALL). The study's main aim is to see if maternal folate supplementation during pregnancy protects against ALL in the child. Researchers collected information on supplemental and dietary folate, environmental exposures, and genetics in determining the risk of childhood ALL.

Findings published in 2009 showed that taking folic acid or other vitamins during pregnancy did not change the child's risk of ALL. There was some evidence that taking folic acid before pregnancy may slightly reduce the risk, but this needs to be looked at further in larger studies. When we combined our results with those of other studies from around the world, there was evidence that taking multi-vitamins during pregnancy may reduce children's risk of getting ALL; however, the specific vitamin responsible for this association could not be identified.

Other findings in 2009 showed that greater than expected fetal growth resulted in a higher risk of developing ALL in childhood.

We think this is related to hormonal factors that are completely outside the mother's control, and we plan to do more research on the reasons for more rapid fetal growth.

Brain tumours

Brain tumours are the second most common cancer affecting children and primitive neuroectodermal tumours of the central nervous system (CNS-PNETs) are the most common type of paediatric brain tumour.

Five-year survival rates have remained in the 50 to 70 per cent range for at least 20 years and children with these brain tumours face the possibility of brain damage and disability associated with surgery, radiotherapy and chemotherapy.

Laboratory research

The main priority of the brain tumour research program is to develop a better understanding of the underlying genetic abnormalities that lead to the generation of a brain tumour cell from a normal brain cell. More specifically, we are looking at neural stem cells in the developing fetal brain as the development of CNS-PNETs is likely to be linked to the genes that function in the pathways that regulate critical aspects of stem cell growth. We are also using our unique panel of CNS-PNET cell lines, which were established from primary patient specimens obtained locally, to test chemotherapy drugs to determine their sensitivity and resistance profiles. Overall, our approach will allow us to develop more effective and less toxic therapies for children with CNS-PNETs.

Ependymoma is the third most common brain tumour affecting children and remains

incurable in 40 per cent of patients. As is often the case with paediatric brain tumours, survivors of ependymoma are frequently left with devastating long-term neuro-cognitive problems. We are looking at tumour initiation and progression in pre-clinical studies so we can better understand the disease and how it can be more effectively and safely treated.

Epidemiology research

Research is continuing on a national study into the causes of childhood brain tumours. As a sister study to our national leukaemia research, we are investigating genetic, dietary and environmental risk factors for childhood brain tumours. Children up to 14 years of age diagnosed with a brain tumour at one of the nine paediatric oncology units in Australia have been invited to participate, with retrospective recruitment of those diagnosed in 2005 as well as prospective recruitment of those diagnosed in 2006 onwards. Control children are identified using Australia-wide random digit dialing and are frequency matched to children with a brain tumour by age, gender and state of residence. Recruitment of children to the study continued during 2009.

HEALTHY DEVELOPMENT



The Institute has a range of long-term studies to expand our knowledge about what children need for healthy development.

Since 1990, we've been a major collaborator on the Raine Study that is tracking the development of almost 3000 children from the womb to adulthood.

With obesity rates trebling in children and young adults in Australia over the past 20 years, our Growth and Development study is investigating the complex factors that contribute to this issue.

Our innovative Developmental Pathways Project is analysing the relationship between child health and wellbeing and a number of other outcomes, including education and delinquency.

Childhood obesity

Childhood obesity is a major health problem which can continue into adulthood and is associated with serious medical complications including Type 2 diabetes, cardiovascular risk factors, sleep apnoea and musculoskeletal pain as well as psychosocial problems such as low self-esteem and depression.

Our Growth and Development Study is looking to identify the factors that contribute to the development and persistence of overweight and obesity in children. They are also interested in the factors that lead from overweight and obesity to the development of medical and psychosocial complications. So far, 1556 primary school aged children have been weighed and measured at school, of which 470 are taking part in the medical/psychosocial assessment.

Developmental Pathways in WA Children

The Developmental Pathways in WA Children Project is a landmark project investigating the pathways to health and wellbeing, education and juvenile delinquency outcomes in Western Australian children and young people. It involves a number of industry partners and government departments. Underpinning the research is WA's unique ability to link together de-identified data from the Institute and government departments to create a powerful research tool. The data being linked as part of the project includes data on hospital and emergency admissions, child protection, education assessment, intellectual disability, birth defects, cerebral palsy, and juvenile justice.

In 2009, research findings from this project revealed a link between healthy growth in the

womb and improved numeracy and literacy skills in early primary school. Healthy fetal growth not only helps to improve a child's performance at school, but it may also contribute towards closing the achievement gap for children from disadvantaged socioeconomic backgrounds. The findings reinforce the need for better integration of health and education policy and services. This was the first time that de-identified birth and educational information from more than 55,000 children were linked to identify some of the broad factors that are linked to educational success.

Raine study

The Western Australian Pregnancy Cohort (Raine) Study is a longitudinal study that began in 1989 by recruiting nearly 3000 women at around 18 weeks of pregnancy. Pregnancy and birth data were collected at Perth's King Edward Memorial Hospital and the study participants are involved in regular follow-up assessments at the Institute. The Raine Study is looking at how events during pregnancy and around birth subsequently influence health and developmental outcomes. It is one of the world's largest and most successful studies of pregnancy, childhood and adolescence.

During 2009, we completed the 17-year follow-up with 1258 teenagers coming to the Institute for an intensive 6-hour assessment. They also completed several questionnaires, provided blood and DNA samples and wore a pedometer for a week to record physical activity. The information collected over the years by the Raine Study has allowed research to be conducted in a number of areas with recent results looking at nutrition, breastfeeding, cardiovascular disease, stress, mental health, non-alcoholic fatty liver disease

and polycystic ovarian syndrome. Planning began for the 20-year follow-up which will commence in 2010 with a focus on eye and reproductive health.

Diabetes

Insulin is necessary for the cells in the body to convert glucose to energy. Type 1 diabetes is an autoimmune disease where the pancreas no longer produces insulin, and is the most common form of diabetes in young people. Type 2 diabetes is caused when insulin is not working effectively or is not produced in the amount needed, and is more common in adults. However, more children are now getting Type 2 diabetes due to being overweight or obese.

Our diabetes research team is looking at clinical aspects of metabolism in children with a focus on insulin therapy in diabetes and reducing acute and chronic diabetes complications. The other areas that the team is involved in are (1) exercise programs and intervention therapies to reduce the risk of diabetes and its complications; (2) testing new methods of detecting risk of diabetes and its complications; (3) investigating diabetes prevention treatments in collaboration with national and international study groups; and (4) trialling novel therapies for severe obesity.

LOOKING at Language

LOOKING at Language is a 10-year study of language development and disorders in twins and singleton children. We are investigating genetic and environmental influences on normal and impaired language acquisition in 1000 West Australian children at two, four, six and nine years of age. Our results to date have shown that early language delay is governed far more by basic biological

processes than environmental circumstances and that one in five children with early language delay are at risk for language impairment at seven years of age.

Cardiovascular disease

In 2009, we published research which showed that almost 30 per cent of 14-year-old Australian children fall within a group identified as being at future increased risk of cardiovascular disease with features of metabolic syndrome. Metabolic syndrome is a collection of disorders which increases the risk of heart disease, type 2 diabetes and stroke. The study found that 29 per cent of children were in the high-risk category at the age of 14 years and even at the age of eight years, 25 per cent of children were at increased risk of future obesity, cardiovascular disease and diabetes.

Gestational diabetes

Gestational diabetes (GDM) is a form of diabetes that appears during pregnancy and usually disappears after the birth of the child. If left unmanaged, the disease can have serious effects on the developing fetus and the mother. Our research examined the trends in GDM, the relationship between GDM and hospitalisation outcomes for mother and child, and the short-term hospitalisation cost to the health system associated with a diagnosis of GDM. Preliminary results indicate that the rate of GDM in WA rose significantly from 1998 (34.3/1000 births) to 2007 (46.3/1000 births). The research indicated that GDM is associated with elevated short-term costs to the health system due mainly to mother hospitalisations around the time of birth. Analyses on child hospitalisations are continuing and the project will be completed in 2010.

INFECTIOUS DISEASE



The global threat of swine flu renewed awareness about the threat of infectious diseases, particularly for the very young and the elderly. Infectious diseases are still the most common cause of death in children and the most common reason that children under two years of age are admitted to hospital.

World-wide, 10 million children under the age of five die from infection each year.

Our research teams are evaluating new vaccines for a range of diseases such as influenza and meningitis.

Common infections such as otitis media (glue ear) can cause life-long problems by seriously impairing hearing and speech, schooling and subsequent wellbeing.

Acute lower respiratory infections

Acute lower respiratory infections (ALRI), or chest infections like influenza and pneumonia, are a major cause of illness in young children. We have been looking at these infections in almost 250,000 Western Australian children born during a 10-year period. We identified 26,106 hospital episodes for ALRI between 1996 and 2005 which included whooping cough, pneumonia, bronchiolitis and influenza. Just under one third of these ALRI episodes were in Aboriginal children, highlighting the disproportionate burden of ALRI in Aboriginal children compared to non-Aboriginal children. We looked at some of the factors leading to increased risk of ALRI for both Aboriginal and non-Aboriginal children and they include being born in autumn, male gender and maternal smoking during pregnancy.

Otitis Media

Otitis media (OM) is an infection of the middle ear with inflammation of the middle ear cavity. It is the most common reason for children to visit a physician in the first years of life, for antibiotic treatment and for surgery in young children.

Our previous research in the Kalgoorlie region reported high rates of OM, particularly in Aboriginal children, and associated hearing loss and an increased risk of OM among children exposed to environmental tobacco smoke. Following on from those findings, we are now developing and implementing an ear health promotion program in the Kalgoorlie region with the aim of having Aboriginal children hearing well by the time they start school. A training workshop with Aboriginal Health

Workers and Community Health Nurses took place during 2009 and ear screening began in Kalgoorlie, Laverton, Leonora and Coolgardie. In the first six months of the project, 61 Aboriginal children under five years of age were enrolled and had their ears checked.

Streptococcus pneumoniae

The bacteria *Streptococcus pneumoniae* (pneumococcus) can cause middle ear infections and invasive pneumococcal diseases such as meningitis, pneumonia and septicaemia (blood poisoning). The Australian Aboriginal population has one of the highest reported invasive pneumococcal disease rates in the world. The existence of 92 known strains of the bacteria increases the challenge of prevention. Vaccines cover some of the strains, but not all. The pneumococcus bacteria is found in the back of the nose of healthy as well as sick individuals. This study is collecting nasal and ear swabs from Aboriginal children and adults so we can determine which strains are currently circulating in the population, the impact of vaccines and give a conservative estimate of the antibiotic resistance of invasive pneumococcal strains.

H1N1 Swine 'flu

Influenza (or the 'flu) is a highly infectious disease caused by a virus and can be associated with serious complications including pneumonia. A new strain of the influenza virus emerged in Mexico and the United States early in 2009. This new strain is known as H1N1 or swine 'flu and is thought to have originated from an Influenza virus that infects pigs. It is different to existing human influenza strains and the 2009 influenza vaccine was not

expected to offer any protection against this H1N1 strain.

In August 2009, our Vaccine Trials Group began testing of a new vaccine to protect against swine 'flu in children aged between six months and eight years of age (inclusive). Trials had already taken place in adults and this was the first study of the vaccine in children. There was no live virus in the vaccine, which is made the same way as standard flu vaccines, so there was no chance of catching the infection from the vaccination. Three hundred and seventy children nationwide were part of the trial with 89 recruited in Perth. The H1N1 influenza strain was included in the 2010 seasonal 'flu vaccine.

Meningococcal disease

Meningococcal disease is a severe and rapid-onset infection which can result in death within hours, due to septicaemia (blood poisoning) or meningitis. It is caused by a bacteria called *Neisseria meningitidis*, which is commonly found in the nose and throat of humans but can occasionally cause disease. Meningococcal meningitis is a significant worldwide threat to the health of children and young adults. The B strain is the most common type of meningococcal disease in Western Australia, accounting for about 90 per cent of cases. Most cases of meningitis, including meningococcal B, occur in babies and young adults. The highest incidence is in infants aged from one month to one year with a second peak in adolescents. There is currently no vaccine to protect against the B strain of this disease.

Our Vaccine Trials Group have been trialling

a Meningococcal B vaccine in adolescents aged between 11 and 18 years. The study follows on from previous Meningococcal B studies conducted during 2008 in young adults, adolescents and toddlers. The vaccine was well tolerated and preliminary results showed protective antibodies against different group B strains.

Whooping cough

Whooping Cough or Pertussis is a highly contagious bacterial disease which affects the respiratory system and produces spasms of coughing that usually end in a high-pitched intake of breath, which is what is referred to as the "whoop." It is a serious disease, especially for young babies. The bacteria lives in the mouth and nose of infected people and is spread through coughing and sneezing. It can easily be spread from parent to child or from child to child. Adults normally have milder symptoms but children can have fever, coughing, vomiting and difficulty breathing. Complications include pneumonia, seizures, brain damage and death.

In Australia, hospitalisations and deaths from Whooping Cough occur in babies less than 2 months of age. At present, a vaccine that can protect against Whooping Cough is first given to babies when they are between six and eight weeks old. In a study by our Vaccine Trials Group, we are hoping to protect babies against Whooping Cough from birth and therefore decrease complications of this serious disease. Newborn babies are given the Pertussis vaccine earlier than eight weeks of age, the time when it is normally given on the Childhood Immunisation Schedule.

SOCIAL & EMOTIONAL WELLBEING



One in six children is affected by a mental health problem. Depression is not only more common, but the average age of onset has become progressively earlier in recent decades. Our research is tracking the range of risk and protective factors that affect mental health and behaviour. One major area of interest is whether the changing diet of Australian children is impacting on their mental health.

The Institute also has a major focus on suicide prevention. We've developed support packs to help anyone concerned about someone who may be depressed or suicidal and for people who have been bereaved by suicide. For every death by suicide, it is estimated that up to 10 people are intimately affected by the loss.

Alcohol in pregnancy and child behaviour outcomes

Research published in 2009 found evidence that the amount and timing of alcohol consumption in pregnancy affects child behaviour in different ways. The analysis was drawn from a random sample of more than 2000 mothers who completed a questionnaire three months after the baby's delivery, and were then followed up when the child was two, five and eight years of age. Mothers who reported what we would classify as heavy drinking in the first trimester of pregnancy were nearly three times as likely to report that their child suffered with anxiety and/or depression or somatic complaints. Those who drank moderately during the first trimester were twice as likely to report those types of behavioural issues for their child. Exposure to moderate or heavy levels of alcohol in late pregnancy increased the risk of aggressive types of behaviours in the child. In this study low levels of alcohol did not increase the risk of harm to the baby. However, the evidence clearly shows that the risk to the baby increases with increasing amounts consumed. Moderate exposure is classified as drinking three to four standard drinks per occasion - about two normal glasses of wine - and no more than a bottle of wine drunk over a week. Heavy drinking included women who were drinking the equivalent of more than a bottle of wine per week.

ARBOR

Following a suicide, early intervention is important to assist in normalising the grief process, to facilitate the identification of those more at-risk and to reduce the risk of

suicide and suicidal behaviours amongst those bereaved by the suicide.

The ARBOR (Active Response Bereavement OutReach) Service continued to support people bereaved by suicide during 2009. The service offers peer support (volunteers bereaved by suicide who are trained to support those newly bereaved), short term counselling, home visits and support groups. It works closely with other support services and the community to provide support services tailored especially for family and friends who lose a loved one to suicide. Research on client outcomes and the wellbeing of peer supporters involved with ARBOR is being undertaken.

Breastfeeding and mental health

Breastfeeding has a beneficial effect on overall childhood health and development and the World Health Organization recommends exclusive breastfeeding for the first six months of life.

We published research results in 2009 which showed that children who are breastfed for longer than six months have a lower risk of mental health problems as they enter their teen years. The research team analysed data from more than 2000 children involved in the Raine Study. Just over half were breastfed for six months or longer, 38 per cent were breastfed for less than six months and 11 per cent were not breastfed. The participants underwent a mental health assessment when they were two, five, eight, 10, and 14 years old. At each of the assessments, the research team found a link between breastfeeding duration and behaviour. For each additional month of breastfeeding, the behaviour score improved. This remained valid

after adjustment for socio-economic, social and other factors impacting on parenting.

Stress and brain development

Our neuroscience research group is looking at the influence of stress around the time of birth and other psychosocial and environmental factors on newborn, child and adolescent health, with a particular interest on how these affect the development of stress adaptiveness, cognition and behaviour. Researchers are collecting information from both the Raine Study and the Peel Child Health Study on stressful life events, family functioning and mental health status as well as growth patterns during and after birth, and genetic information. We are also conducting stress responsiveness tests with 18-year-old participants from the Raine Study, with 1000 stress tests completed at the end of 2009.

Dietary patterns and mental health

Research findings published in 2009 showed a link between Western-style diets and more mental health problems in teenagers. The results were based on detailed analysis of diet records and behaviour checklists that were collected from more than 1600 West Australian 14-year-olds in the Raine Study. Higher levels of behaviour and emotional problems were associated with a more Western-style way of eating, namely a diet high in takeaway foods, red meat, confectionary, soft drinks, white bread and unrefined cereals. These problems were less prevalent among teens with a more healthier style of eating, specifically those who ate more fruit and vegetables. The study participants' food intake was assessed using a

212-item food frequency questionnaire. The Child Behaviour Checklist was used to assess internalising mental health problems, such as withdrawn and depressed behaviours, and externalising mental health problems, such as delinquent and aggressive behaviours.

Smoking and child behaviour

New research published in 2009 showed that even if a woman is still smoking in the first few months of pregnancy, it is not too late to quit to improve the outcomes for her child. The analysis revealed an association between mothers who quit by four months gestation and a reduced risk of behavioural problems in the child. The analysis was drawn from data collected from more than 2800 participants in the Raine Study. Behaviour was assessed at two, five, eight, 10 and 14 years of age. The study also showed that smoking throughout pregnancy results in a much higher risk for behavioural problems in children than those children whose mothers did not smoke, or quit smoking before four months gestation. One in six women still smoke in pregnancy.

Indigenous Mental Health Textbook

This project was a collaboration between the Australian Council for Education Research (ACER) and the Institute's Kulunga Research Network. The book offers new approaches to Indigenous mental health that acknowledge the importance of cultural identity and resilience as well as the pervasive effects of racism, and the disempowerment of colonisation and assimilationist policies. The book incorporates specific clinical mental health assessment processes and culturally appropriate treatment interventions.



THE EARLY YEARS

There is a growing body of research that shows the importance of early brain development. How children are nurtured and stimulated in their first five years of life affects their development in many ways, including how they perform at school and how they handle the stresses in life.

The Institute is a prime mover in the national roll-out of the Australian Early Development Index – a powerful tool for communities to see just how well their children are faring, even before they start school.

Australian Early Development Index

The Australian Early Development Index (AEDI) is a nation-wide program that looks at the development of young children. The results give communities in Australia a snapshot of how children have developed in the years before they begin school. It helps communities and governments pinpoint the services, resources and support young children and their families need to give children the best possible start in life.

The AEDI is being conducted by the Centre for Community Child Health (at The Royal Children's Hospital Melbourne, and a key research centre at the Murdoch Childrens Research Institute) in partnership with the Telethon Institute.

In 2009, the AEDI was completed nationally, providing the first national census of early child development. The AEDI results show that around two-thirds of children are doing well in five key developmental areas with 23 per cent of children developmentally vulnerable in one area, and more than 12 per cent vulnerable in two or more developmental areas.

The 2009 AEDI results are based on data gathered by teachers on more than 260,000 children around Australia as they entered their first year of full-time school. The AEDI measures five key areas of early childhood development: physical health and wellbeing, social competence, emotional maturity, language and cognitive skills, communication skills and general knowledge.

The support of Shell in Australia is enabling the AEDI Indigenous Adaptation Study which

is developing and evaluating a culturally-appropriate version of the AEDI to measure Indigenous children's early development status and readiness for school at a community level. The project is adapting the teacher-completed checklist, the teacher guidelines and the dissemination of AEDI results in Indigenous communities.

Internationally, the Institute is part of a consortium to support other countries with an interest in monitoring child development. The Institute is currently working with Indonesia, the Philippines, Jordan and Peru in their endeavours to adapt the EDI.

Assisted reproductive technologies (ART)

In 2009, we looked at hospital admissions during the first three years of life for all twin children born in Western Australia between 1994 and 2000. Seven hundred of these twin pairs were born following assisted reproductive technology (such as IVF) and 4097 were conceived spontaneously. Twins born after ART had a greater risk of pre-term birth, low birth weight and death compared with spontaneously conceived twins of unlike-sex. In their first year of life, ART twins also had a longer birth admission, were 60 per cent more likely to be admitted to a neonatal intensive care unit and had a higher risk of hospital admission. This information is important for couples considering fertility treatment.

Nutrition and DNA health

We know that, in adults, poor DNA health may be linked to serious diseases like cancer. Previous studies have shown that adults

who have poor DNA health often lack vital micronutrients. However, there is no research or information available about these links in children. A new study is looking at nutritional and genetic factors that may be associated with DNA damage in children. Four hundred and fifty West Australian children will be recruited into the study and we will assess their diets and macro-and micro-nutrient intake. Blood samples will provide important information about micronutrient levels, biomarkers of DNA damage and genetics. Saliva samples will provide indicators of psychological stress and exposure to environmental tobacco smoke.

Peel Study

In collaboration with Murdoch University, the Institute is undertaking a world-first health project in the Peel region aimed at building better communities for children.

The study will track hundreds of children from conception to teenage years, giving researchers unparalleled insight into child development. The growing Peel region has a high proportion of young families and the study will track these children to see how their biological make-up is affected by the environment in which they live. The study will look at physical, social and family environments including education, culture and recreation. The study will seek to find out how the community impacts on child development and how it can help create a healthy environment for children.

It is expected about 2000 families will take part in the study with mothers enrolled at 18 weeks of pregnancy. Information collected

will include stress during pregnancy, maternal lifestyle, ultrasound scans, and stress hormone levels in blood, saliva and urine. In 2009, recruitment continued with 200 families enrolling into the study.

Baby friendly hospital initiative

Breastfeeding is internationally recognised as the optimal method of infant feeding. A large body of research exists indicating that breastfeeding results in a number of positive health outcomes for both infant and mother. The World Health Organization recommends exclusive breastfeeding for the first six months of life. Based on the benefits of breastfeeding, and the low adherence to international infant feeding recommendations observed in Perth, a need for strategies and interventions aimed at improving the duration of breastfeeding practice within Western Australia has been identified. The WA Department of Health, through the Women's and Newborns' Health Network, has developed a state-wide policy for all staff working in hospitals with pregnant women and new mothers, called the Baby Friendly Health Initiative - hospital breastfeeding policy. The Institute is evaluating the effectiveness of the policy roll-out in terms of its impact on hospital adherence to practices conducive to breastfeeding and infant feeding practices in WA. The evaluation will take place at two time points and involve 2700 WA mothers of babies over six months of age. Telephone interviews will be conducted to collect information about breastfeeding practices and mothers' experiences in hospital. The first wave of mothers will be recruited in 2010 across all health regions in WA.

UNDERSTANDING DISABILITY



Around eight per cent of children in Australia live with a disability. At the Telethon Institute our focus is on understanding the causes of disability, so they can be prevented.

That's what we did with neural tube defects (NTD) like spina bifida. Our researchers were part of the international collaboration that identified that taking the vitamin folate in the months before conception would reduce the risk of an NTD by up to 70 per cent. We've now advocated for the mandatory fortification of food with folate so that these health benefits are available to all families.

Our focus on disability also includes our ground-breaking work on cerebral palsy and extensive research projects in Rett syndrome, Fetal Alcohol Spectrum Disorders and birth defects.

Alcohol and pregnancy

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term that describes the range of effects of maternal alcohol consumption during pregnancy, and includes Fetal Alcohol Syndrome (FAS). It is a preventable condition.

In 2009, following the release of the *Australian Guidelines to Reduce Health Risks from Drinking Alcohol*, we reviewed, revised and reprinted our alcohol and pregnancy resources for health professionals. They have now been distributed extensively across Western Australia and we have made them available to health professionals throughout Australia (www.ichr.uwa.edu.au/alcoholandpregnancy).

Hypospadias

Hypospadias is a birth defect in boys that affects the penis. Around one in every 130 boys in Western Australia has the condition and this has been increasing in recent years. Boys with the condition may have problems urinating and fertility problems as adults. Hypospadias can be fixed with surgery.

Results published in 2009 from a new study found a possible association between parental occupations and hypospadias. The results are preliminary and require further investigation. The study looked at the parents' occupations of more than 1200 boys with hypospadias and compared them with the occupations of the parents of more than 2500 boys without hypospadias. Potential exposure to seven different types of (endocrine disrupting) chemicals was assessed for 348 parental occupations and then compared between cases and controls. Endocrine disrupting chemicals mimic female hormones and can

disrupt the production of male hormones. The research found that mothers who may be exposed to heavy metals in their occupations were two and a half times more likely to have a son diagnosed with hypospadias. Women working in the dental industry, defence forces, as laboratory workers and in petrol stations were identified as being potentially exposed to heavy metals. Women who were potentially exposed at work to phthalates (chemicals used in a wide variety of products including plastics, detergents and personal care products, such as deodorants, fragrances, nail polish and hairspray) were also at higher risk. What remains unknown is the timing or the frequency of exposure to chemicals or even whether the parent was in fact exposed during pregnancy.

Rett syndrome

Rett syndrome is a rare but serious neurological disorder that affects around one in every 8,500 female births in WA. It is caused by a mutation in the *MECP2* gene on the X chromosome and there is no cure.

In 2009, we published a comprehensive guide on the management of scoliosis in girls with Rett syndrome. The guidelines were developed in response to limited professional literature about the clinical management of Rett syndrome. Scoliosis is a common orthopaedic complication of Rett syndrome with about three quarters affected by the age of 13 years. These guidelines take a life-span approach, commencing before the development of scoliosis and including comprehensive management from medical, therapy and surgical specialists.

A research collaboration between Australia and Israel identified a genetic variation that influences the severity of symptoms in Rett syndrome. Clinical information and DNA samples were gathered from 125 patients from the Australian Rett Syndrome Database and an Israeli cohort and showed a correlation between the severity of clinical symptoms and a common brain-derived neurotrophic factor (BDNF) polymorphism. This information is potentially helpful in predicting the clinical progression of Rett syndrome and provides another area to explore for potential therapies.

Autism Spectrum Disorders

Autism Spectrum Disorders (ASD) is an umbrella term describing autism, Asperger syndrome and Pervasive Developmental Disorder Not Otherwise Specified. They are characterised clinically by significant impairment in social interaction and communication and the presence of unusual behaviours. Many children have difficulty integrating into society and require varying degrees of supervision and support in daily living.

Globally, significant increases in ASD prevalence have been reported. In 2009, we found that the rapid increase in the number of children diagnosed with ASD in Western Australia reflects closely changes to diagnostic practices and provision of services. The study found that in 1983, 1.7 in every 10,000 children born in WA were diagnosed with ASD by age eight compared with 53.4 per 10,000 children born in 1997, representing a 16.6 per cent increase per annum. While a true increase in prevalence cannot be ruled out, the increase over this period was shown

to coincide with local changes to the way autism has been diagnosed and how early intervention services have been funded.

In another study, Institute researchers found that girls with higher testosterone levels at birth are more likely to have poor communication skills and social difficulties at age 10. The study was particularly interesting in the context of the emerging theory of autism as an extreme form of male brain development. The girls in the study were more likely to have social difficulties, but didn't score higher on positive traits linked to maleness, such as spatial awareness and problem-solving ability. The findings are another piece of evidence that we might be on track to better understand what causes autism, and therefore, a step closer to better interventions and prevention.

Cerebral Palsy

Cerebral palsy (CP) is a chronic neurological condition resulting from damage to the brain before birth, around birth or in early childhood. CP affects movement and posture and can also be accompanied by epilepsy, defects in intellect, vision, hearing, speech and spatial awareness, and musculo-skeletal problems. CP results in a life-long disability and as there is no cure, prevention and effective management are top priorities.

The Institute manages the WA Cerebral Palsy Register which has been in existence for 30 years and now contributes data to the Australian CP Register, based in NSW. We have also been developing a reliable system for classifying CP subgroups as there is a wide range of motor impairments across the spectrum of severities and consistency in classifying is essential.

Senior staff



Jenefer Blackwell *BSc(Hons) PhD FMedSci HonDSc (U. Khartoum) DSc (Cantab)*
Genetics and Health Laboratory

Originally from Perth, Professor Blackwell has held positions at the London School of Hygiene and Tropical Medicine (1975-1991) and the University of Cambridge (1991-2007) in the UK. She established, and was the Founding Director of, the Cambridge Institute for Medical Research. In 2007, she joined the Telethon Institute and established the Genetics and Health Laboratory. Professor Blackwell has a long-standing interest in complex disease genetics. Current projects include genome-wide studies of visceral leishmaniasis from India, Brazil and Sudan, otitis media and metabolic diseases in Indigenous Australians, and type 2 diabetes as a risk factor for sepsis in Thailand. Professor Blackwell holds a Winthrop Professorship at The University of Western Australia and is an Affiliated Principal Investigator at the Cambridge Institute for Medical Research and Honorary Senior Scientist in the Department of Medicine, University of Cambridge School of Clinical Medicine, UK.

Carol Bower *MBBS MSc PhD FAFPHM DLSHTM FPHAA*
Epidemiology

As one of the Institute's founding senior researchers, Professor Bower has been a driving force behind its epidemiological research program, in particular in birth defects. In the 1980's and 1990's, Professor Bower was part of the international team that showed the link between folate intake during pregnancy and the reduction in neural tube defects and in 2007 was awarded a Leadership Award from the Flour Fortification Initiative for her folate advocacy role. In addition to folate, Professor Bower is also leading research projects into other factors that can influence health outcomes of newborn babies including alcohol consumption, prescription medication and *in-vitro* fertility treatment.

Nick de Klerk *BSc MSc PhD*
Bioinformatics

An Adjunct Professor at The University of Western Australia, Professor de Klerk was originally trained in the United Kingdom. He was Head of the Occupational Respiratory Epidemiology Group in the Department of Public Health at UWA before joining the Institute in 2000. Professor de Klerk's knowledge and expertise in statistically analysing scientific data sees him collaborating with the majority of the research groups within the Institute. In 2008, he co-authored 25 research papers with Institute staff and has continued to oversee the success of the Developmental Pathways in WA Children Project which is looking at the pathways to health and wellbeing, education and juvenile delinquency outcomes among WA children and youth.

Michael Garlepp *BPharm BSc(Hons) PhD MPS*
Director, Academic and Research Services (to Dec 09)

Professor Garlepp joined the Institute in 2008 from Curtin University where he was Head of the School of Pharmacy and served as Acting Executive Dean for the Division of Health Sciences for an extended period. Professor Garlepp has also worked as a full-time biomedical researcher in the Faculty of Medicine and Australian Neuromuscular Research Institute at UWA. Recognised internationally for his studies of the genetics of inflammatory muscle disease, Professor Garlepp expanded his research into gene therapy to look at ways of using genetic modification to improve immunity to cancers including mesothelioma. He is currently Deputy President of the Pharmaceutical Council of WA.

Prue Hart BSc(Hons) MSc PhD

Inflammation Laboratory

Professor Hart joined the Institute in 2003, following positions at The University of Queensland, Rigshospitalet in Copenhagen, The University of Melbourne and Flinders University. At the Institute, Professor Hart's team focuses on the effects of ultraviolet radiation and vitamin D3 on the immune system with their ground-breaking work showing that UV irradiation of mice, with doses equivalent to a short period in the midday sun, can be protective against developing asthmatic symptoms. The research is now looking at teasing out this protective mechanism with the goal of one day being able to use UV light in safe doses or vitamin D3 to prevent and/or treat asthma. Professor Hart also has a research programme examining the mechanisms by which interleukin 4 may limit the activity of the immune cells driving chronic inflammation. Professor Hart is a NHMRC Principal Research Fellow and an Adjunct Professor at UWA.

Pat Holt PhD FRCPath(UK) DSc FAA

Deputy Director, Cell Biology

Professor Holt established the Division of Cell Biology at the Institute's inception in 1990 with his research group's main focus being on the functioning of the paediatric immune system in relation to asthma and allergy. Professor Holt has established collaborations both locally and internationally and his research is highly regarded by researchers and clinicians alike. In 1999, Professor Holt was presented with the King Faisal International Prize for Medicine, one of the world's pre-eminent scientific awards, in recognition of his significant contribution to the improved understanding of asthmatic disease. He is a Senior Principal Research Fellow of the NHMRC and Professor at The University of Western Australia.

Ursula Kees Dip Phil II PhD

Leukaemia and Cancer Research

Professor Kees was one of the founding research leaders of the Institute, establishing the Division of Leukaemia and Cancer Research in 1990. Prior to this, the Swiss-born scientist was recruited from the German Cancer Research Centre in 1984 to head up the Children's Leukaemia & Cancer Research Laboratory at Princess Margaret Hospital. Focusing on molecular genetic markers which lead to cancers in children, Professor Kees' team has developed unique methods to diagnose different cancers in collaborative studies with hospital patients and oncologists and a number of overseas groups. Professor Kees holds an Adjunct Professorship at The University of Western Australia.

Deborah Lehmann MBBS, MSc

Infectious Disease Epidemiology

Professor Lehmann joined the Institute in 1998 following 18 years at the Papua New Guinea Institute of Medical Research leading studies into pneumonia. Today, she maintains strong ties with Papua New Guinea, in particular through a vaccine trial looking at the safety and immunogenicity of pneumococcal vaccines in newborn infants in Papua New Guinea. Professor Lehmann is also leading research on respiratory infections in Australian children and heads an Indigenous Capacity Building Grant. In 2007, Professor Lehmann received a WA Public Health Association of Australia Award for her outstanding contribution to public health. She is a Clinical Associate Professor at The University of Western Australia and an Associate Professor at Curtin University.



Senior staff



Bruce McHarrie *BCom FCA*

Director, Finance and Business Development

Mr McHarrie took up the position of Director of Finance and Business Development in 1999 after returning to Perth from the UK. In the UK, he held positions with Coopers & Lybrand Deloitte and Rothschild Asset Management where he was Assistant Director of the Bioscience Unit. Mr McHarrie oversees the financial and executive management of the Institute, as well as developing public relations and fundraising activities. He is also responsible for the commercialisation opportunities arising from the Institute's research program and holds the position of Non-Executive Director of Phylogica Limited and Advanced Diagnostic Systems Pty Ltd, being two Institute spin-out companies.

Glenn Pearson *B Art (Education)*

Kulunga Research Network

Mr Pearson has been with the Institute's Kulunga Research Network for five years having worked within the Australian and State Governments in the areas of health, education and child protection. He brings with him 15 years experience in strategic policy, program development and service delivery. He is currently completing a PhD through the School of Paediatrics and Child Health at The University of Western Australia. His project is one of six research projects undertaken as part of the Developmental Pathways for WA Children Project and will explore the delivery of community health, education and child protection services by the WA State Government to Aboriginal people in the Perth Metropolitan and Geraldton regions. His work within the Institute has included a number of Kulunga's key research projects such as the WA Aboriginal Child Health Survey.

Peter Sly *MBBS MD DSc FRACP*

Clinical Sciences

Professor Sly established the Division of Clinical Sciences at the Institute in 1991. Two of the major themes of study in the Division include asthma and cystic fibrosis and more recently, Professor Sly has overseen the establishment of the WHO Collaborating Centre for Research on Children's Environmental Health. One of only two of its kind worldwide, the Centre is focussed on investigating environmental factors that promote the vulnerability of children to lung disease such as air pollutants and household chemicals, with a view to promoting stronger public health messages about the dangers of such factors. Professor Sly is also a respiratory physician at Princess Margaret Hospital and a Professor at UWA.

Wayne Thomas *BSc (Hons) PhD*

Molecular Biotechnology

Professor Thomas, who currently holds a Senior Principal Research Fellowship from the NHMRC, joined the Institute at its inception in 1990 and established the Division of Molecular Biotechnology. Research in Professor Thomas' laboratory is focussed upon the mechanisms of inflammation and allergy and the development of methods to treat or prevent diseases resulting from these processes. Professor Thomas has a particular interest in using molecular biology techniques to identify and characterise allergens from house dust mites and cats. These are then used in further laboratory research into allergy and may one day be useful in desensitisation therapy for allergic individuals.

Sash Tomson *BCom CPA FAIM*

Chief Administrative Officer

Mr Sash Tomson joined the Institute in 2009. He was previously an Executive Director with the Queensland Department of Education and Training and held senior executive positions with the Departments of Communities and Emergency Services, Queensland. In January 2004 he received an Australia Day Medal for his work with the Queensland Ambulance Service, and later that year was admitted as a Fellow of the Australian Institute of Management. Prior to his role in the public sector he was Senior Manager, Assurance and Advisory Services with KPMG, Brisbane. His career has involved providing corporate and strategic services to clients within the public and private sectors. Sash has responsibilities for corporate, strategic and company administrative support.

Paul Watt *BSc (Hons) D.Phil*

Drug Discovery Technology Unit

An Adjunct Professor at The University of Western Australia, Professor Watt obtained his PhD at Oxford University before completing post-doctoral training at Oxford and Harvard Universities. Upon returning to WA, he joined the Institute's Division of Leukaemia and Cancer Research and now heads the Drug Discovery Technology Unit. In 2001, Professor Watt was a driving force in establishing the Institute's spin-off company, Phylogica Ltd (www.phylogica.com), where he is Executive Director and Vice President of Corporate Development. Professor Watt has led his research team in the development of Phylomer® peptides, molecules designed to target proteins and block their interactions. The Phylomer libraries he has developed constitute the most structurally diverse set of peptides available, resulting in the highest quality and quantity of peptide hits. Phylogica has recently entered into an alliance with Europe's largest pharmaceutical company Roche and is negotiating other discovery collaborations.

Stephen Zubrick *MSc AM PhD*

Population Sciences

A Professor at Curtin University, Professor Zubrick completed his doctoral and postdoctoral work in psychology at The University of Michigan and worked in mental health settings for many years before starting at the Institute in 1991. His research interests include the social determinants of health and mental health in children, systematic studies of youth suicide, and large scale psychosocial survey work in non-Indigenous and Indigenous populations. Professor Zubrick is considered a leading Australian authority in the epidemiology of child and adolescent mental health and in public health approaches to promotion and prevention of mental health. He chairs the Consortium Advisory Group of the Longitudinal Study of Australian Children and featured in the ABC TV's 'Life' documentary series.



Collaborations and joint ventures

UWA Centre for Child Health Research

Established in 2001, the UWA Centre for Child Health Research facilitates closer collaboration with the University of Western Australia, providing access for staff in the Centre to relevant university services including administrative and research services and postgraduate student administration. The Centre for Child Health Research is located within the Faculty of Medicine, Dentistry and Health Sciences, and is closely linked with the School of Paediatrics and Child Health.

Curtin Centre for Developmental Health

The Centre for Developmental Health is a joint venture between the Telethon Institute and Curtin University. This multidisciplinary centre brings together researchers in child and life-course human development with the aim of improving population outcomes in health, education and social wellbeing.

Edith Cowan University

The Institute has a number of collaborative studies with Edith Cowan University, mainly in the area of Population Sciences which has been formalised through the signing of a Memorandum of Understanding addressing joint research and postgraduate teaching opportunities.

Murdoch University

The Institute hosts several Honours and postgraduate research students from Murdoch University, principally in the Division of Molecular Biotechnology. New collaborations in Biomedical and Clinical Sciences as well as Population Sciences are being developed. The relationship between the Institute and Murdoch was formalised in a Collaboration Agreement dated January 9, 2008.

Notre Dame University

Researchers at Notre Dame University Australia have a collaboration with Institute staff on the WA Pregnancy Cohort (Raine) Study.

Princess Margaret Hospital for Children

The Institute continues to have a close working relationship with the state's children's hospital. With the planned relocation of PMH within the coming decade, the Institute and PMH have been developing the concept of a contiguous research and education facility. The close working relationship between medical research, clinical practice and teaching is exemplified in the important areas of children's cancer and leukaemia, infectious diseases and diabetes.

Phylogica

Drug discovery company Phylogica (ASX:PYC) is the first commercial spin-out from the Telethon Institute for Child Health Research. Phylogica's innovative Phylomer® technology targets and blocks disease protein interactions, constituting a drug discovery engine designed to produce cost-effective therapies with fewer side effects than existing treatments.

World Health Organization Collaborating Centre for Research on Children's Environmental Health

In 2005, the World Health Organization (WHO) designated the Institute's Division of Clinical Sciences as a Collaborating Centre for Research on Children's Environmental Health. The Centre is committed to making a significant contribution to research and education in children's environmental health.

Papua New Guinea Buttressing Coalition

The Institute is proud to be a member of the Buttressing Coalition of the Papua New Guinea Institute of Medical Research (PNGIMR). Members share a common interest - to sustain and to strengthen the PNGIMR without jeopardising its integrity. Our Director, Fiona Stanley, is the current Chair of the Buttressing Coalition. We are involved in the Papua New Guinea pneumococcal conjugate vaccine project, and host PNGIMR staff and students for exchange visits.

Prue Hart

Is it any coincidence Prue Hart moved to the sunniest city in Australia to progress her research into the immunoregulatory properties of sunlight?

Prue heads the Inflammation research group at the Institute, looking at UV irradiation, Vitamin D and control of immune responses. Leading a team of eight, Prue facilitates daily experimentation, analysis and planning.

"In the broader picture, we are trying to better understand the mechanisms by which anti-inflammatory and immunosuppressive processes (UV irradiation of skin) or molecules (interleukin-4 or vitamin D3) may work," Prue explains.

Prue's research into the immunoregulatory properties of sunlight first began in the mid 1990s while working at Flinders University in Adelaide. Relocating to the Institute in 2003, after 13 years at Flinders Medical Centre, much of Prue's work switched to using models of asthma and allergic airways disease as the target for these anti-inflammatory and immunosuppressive processes or molecules.

"The involvement of UV-induced vitamin D in our studies has occurred only in the last few years due to the large number of international epidemiological studies suggesting that serum levels of vitamin D may be inversely proportional to outcomes of many tissue cancers (colon, prostate, breast, melanoma) and hyperimmune diseases (multiple sclerosis, diabetes and now asthma)," she says.

"Australians are amongst the best photoimmunologists in the world which is appropriate for a country characterised by intense sunshine and one of the world's highest skin cancer rates."

Originally from the sunshine state capital, Brisbane, Prue achieved a Bachelor of Science (Honours), Master of Science, and PhD from the University of Queensland. Prior to completing her PhD, Prue worked for 18 months at Rigshospitalet in Copenhagen and travelled the world for a further 12 months.

"I realised Australia was where I wanted to be and I needed a PhD for any sort of career in medical research," says Prue.

Completing her PhD with the famous liver group run by Professor LW Powell at the Royal Brisbane Hospital, Prue says at the time the scope in Brisbane for medical research was very limited. She moved to Adelaide to complete her first three-year

post doctoral qualification at Flinders University, the second at the University of Melbourne, before returning to Flinders University with an National Health & Medical Research Council Fellowship to establish an independent research group.

Prue finds a career in research to be very demanding but at the same time, very satisfying.

"Sometimes months can pass without great progress. Then there is always the sweat and tears and experiments that don't work," says Prue. "But every step forward, every manuscript accepted for publication, every talk given where you get questions that suggest that the audience has understood your arguments, is rewarding. You know you are adding only one small piece to the jigsaw but at least you are making some advance. I have one publication in the *Proceedings of the National Academy of the USA* with approximately 1000 citations."

The research road is not always smooth, however, and Prue understands the hurdles for young professionals can be extremely challenging.

"As you develop your career, you learn to cope with many knock-backs of your manuscripts, your grants, your fellowship applications. However, it is very difficult for young researchers to handle such setbacks".

With many close friends still in the eastern states, Prue spends a lot of time keeping in touch, and with some of those friends also in research she has found conferences provide wonderful opportunities for both networking and friendship.

Outside work, Prue says she tries hard to be a good mother for teenage daughters who need her more now than they did when they were in primary school.

"I have been lucky enough to juggle a research career with bringing up two wonderful daughters - I have to acknowledge a wonderfully supportive husband," Prue says. "My daughters both play a lot of sport - I play tennis with the girls when we can, and swim lengths together at Claremont pool on Sunday mornings (admittedly more often than not it is just me)".

Due to the global positioning of Australia, Prue feels it's essential we understand the contribution of our sunny environment on our health and on disease pathogenesis.

"I also want to better understand the pathways by which exposure of skin to sunlight can have these systemic effects."





Consumer and community participation

Consumer and community participation activities at the Institute continued to flourish during 2009 with a steady increase in the uptake of participation initiatives throughout the Institute. In particular, the success of two new initiatives, the training workshops for researchers and the 'Community Conversations,' again emphasised the leadership role the Institute has established in this area.

The Institute and the UWA School of Population Health's long term community engagement strategy gained international recognition when Anne McKenzie, the Consumer Advocate, was invited to present this work at the Sheffield University's School of Health and Related Research and Swansea University in Wales.

Consumer and Community Advisory Council

The Institute's Consumer and Community Advisory Council has now been operating for three years and continues to be involved in a range of activities throughout the Institute. Highlights in 2009 included:

- The establishment of the Consumer and Community Participation Award to acknowledge good practice in consumer and community participation. Jan Payne, a senior research officer working on the alcohol and pregnancy project, was the inaugural recipient of this award.
- Involvement in development and implementation of the 'Community Conversations'. The Council will also have an ongoing role in providing advice to research areas about the feedback from the workshops.
- Presenting the consumer and community perspective at the training workshops for researchers.

Community Conversations

The 'Community Conversations' were established to inform consumer and community members about current research projects and to seek their input in identifying any perceived gaps and priorities for future research. Three 'conversations' were held in June, August and October in the following areas:

Understanding Disability - There was an enormous amount of information generated from the workshop and some of the common topics identified as being important for future research were: family and carer isolation, resilience and functioning; transition from child to adult health services; and fertility, pregnancy and depression for young adults with disability. The information from the 'conversation' will be used to inform planning for current and future research projects.

The Raine Study – 20 Raine Study participants, aged 17 to 20 years old, took part in a conversation to discuss their priorities for future research in the study. Issues relating to mental health, addiction and substance abuse, fertility and cyber-bullying were put forward as priorities. The young people were also asked about staying in the Raine Study and as a result of feedback, a 21st birthday celebration is being considered.

The Developmental Pathways Project also used the 'community conversation' process to gain consumer and community input into the development of research questions for a major grant application.

A common issue raised at all three conversations was the need for easy access to information about research projects, research findings and information about the translation of those findings into policy and practice.

Consumer and community participation training for researchers

In 2009, training workshops were developed for researchers on implementing consumer and community participation in research. This was in direct response to feedback from researchers, who expressed a need for training and ongoing support. The workshops were co-facilitated by Anne McKenzie and Bec Hanley (UK Consumer Advocate).

Three pilot workshops were held in April with 53 researchers from the Institute and the UWA School of Population Health. Following their success, a Summer School course was run in December at UWA where a further 43 researchers attended two-day workshops.

Of the 96 people who attended the training workshops, 83 per cent said they intended to change their practice. This has been evidenced by the increase in participation activities at the Institute.

*Right: Bec Hanley and Anne McKenzie at a training workshop.
Below: Institute disability researcher Jenny Bourke in conversation with community members.*



Corporate & community partnerships



Fundraising in focus

The Children's Future Fund is central to the growth and longevity of the Institute's world-class research. A capital fund with an income stream that supports our world class researchers now and in the future, the growth of this fund remains the focus of the Institute's fundraising efforts.

Fundraising is vital to underpinning the operations of the Institute as well as providing strategic funding for the future. People are our most valuable resource and the Institute needs sustainable funding to retain, develop and recruit current and future research leaders, as well as provide the environment in which they can excel.

Attracting the best researchers and providing a world class research environment leads to the best chances of finding the causes of childhood diseases and disabilities.

Thanks primarily to support from the Federal Government via Telethon to fund research into Aboriginal health and environmental health, income from donations, fundraising, bequests and sponsorship showed a significant increase in 2009 as income reached a total of \$4.48 million - an increase of 32 per cent on the previous year's results.

Fundraising and Corporate Partners

Support from the corporate sector and our founding sponsor, Channel 7's Telethon, provides crucial income to fund specific research projects, emerging researchers and the provision and maintenance of equipment and facilities.

Fundamental to the Institute's success, Telethon, through the generosity of the people of WA, raises money for the children's charities of Western Australia including the world class research of the Telethon Institute. In 2009, we received additional support through Telethon from the Federal Government, to fund research into Aboriginal health and environmental health.

We acknowledge also the visionary support of our many corporate partners in supporting cutting edge research into the health and wellbeing of children and young people. Their outstanding support and generosity provides indispensable funding for ground-breaking research projects and the translation of that research into action that makes a real difference to the lives of children and families.

Pivotal to our success in 2009 has been the support of a number of philanthropic Foundations and Trusts whose confidence in often fledgling or unusual projects has amounted to many great achievements.

Global Philanthropy

The Institute is very proud to be associated with 'NOMAD Two Worlds' and its powerful visualisation of reconciliation in action. As NOMAD's global philanthropic partner, funds raised support the Institute's community-initiated health research and the training of outstanding Aboriginal students in health research.

Created by internationally acclaimed photographer Russell James, with Indigenous Australian artist Clifton Bieundurry and others, the collaborative art project is a stunning example of reconciliation and true cultural collaboration in action. Inspired by the Australian reconciliation movement (initiated by Australian Prime Minister Kevin Rudd's apology speech in February 2008), NOMAD Two Worlds is a merging of modern western culture that settled in Australia some two hundred

years ago and its Aboriginal people, the world's oldest surviving culture.

Aboriginal culture has promoted the link between spirit, land and health for thousands of years. Now our research has shown the impact and power of these links for the psychosocial wellbeing of children and young people. Australian society is starting to recognise the direct effects of loss of land and culture on Aboriginal health and wellbeing; hence the outpouring of support across the nation on the day of the Apology. Russell James has produced powerful works that celebrate reconciliation in action and capture the strength and beauty of our land and Aboriginal culture. The Institute is very excited by our partnership with NOMAD and looks forward to working closely with the NOMAD team in pursuing our common aims of reconciliation and healing.

Our partnership with NOMAD Two Worlds - along with supporters, fashion icon and founder of Urban Zen Donna Karan and international recording artists the Black Eyed Peas - was celebrated at a unique, private preview of these incredible artworks at the National Gallery of Victoria in October 2009.

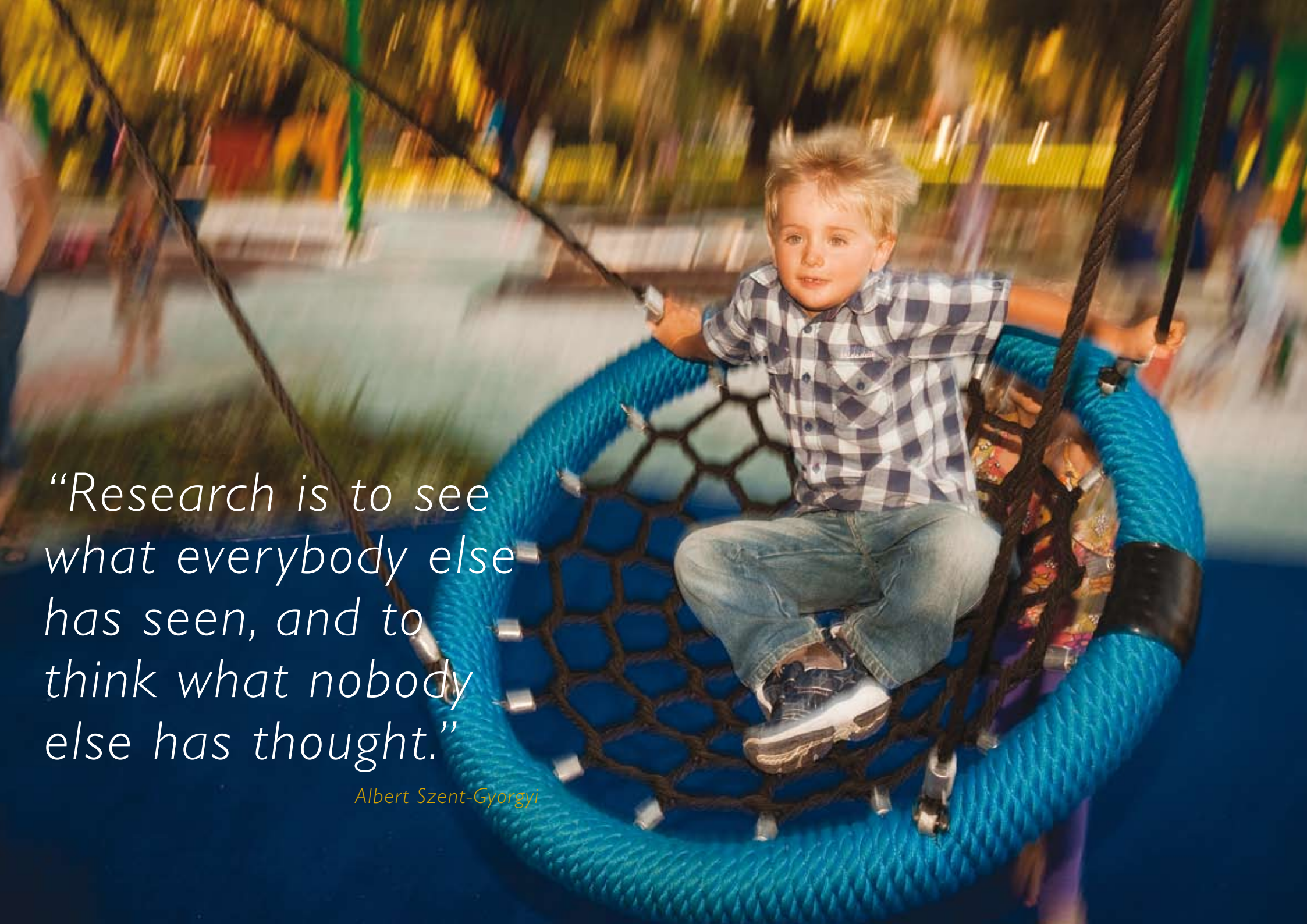


australia's aluminium



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*“Research is to see
what everybody else
has seen, and to
think what nobody
else has thought.”*

Albert Szent-Gyorgyi

Therese O’Sullivan



If anyone can confirm the timeless claim that ‘breakfast is the most important meal of the day’, it’s Dr Therese O’Sullivan.

As a Senior Research Officer for the Raine Study Nutrition Group within the Population Sciences Division, Therese investigates the associations between dietary factors and mental and metabolic health in adolescents participating in the Raine Study.

In 2008, Therese was a recipient of the Dr Louisa Alessandri Memorial Fund Award for Scientific Publication for her research paper ‘A good-quality breakfast is associated with better mental health in adolescence’ published in the journal *Public Health Nutrition*.

Her findings support the concept that breakfast quality is an important component in the complex interaction between lifestyle factors and mental health in early adolescence. Therese presented her research at the Dietitians Association of Australia (DAA) national conference, announcing that based on her research, a high quality breakfast, with foods from at least three different healthy food groups, was linked with better mental health in 14 year old boys and girls. And she found that for every additional food group eaten at breakfast, the associated mental health score improved.

Therese’s work at the Institute also involves the examination of nutrition and dietary patterns in the Raine Study over the years, including the omega-3 index in adolescents and associations with cardiovascular risk factors.

Most people would agree that being paid to think about food all day sounds like a dream job. For Therese, her dedication to nutrition research is an absorbing task - one that she hopes will provide insight to improve long-term health outcomes for generations to come.

“I have a strong interest and curiosity to discover how what we eat can influence our health in the long term,” Therese says.

Therese completed a double undergraduate degree in nutrition and dietetics/exercise physiology at the Queensland University of Technology.

Proving she is not just academically bright but also business savvy, while completing her studies Therese was selected in the Australian delegation for the APEC Young Leaders and Entrepreneurs Forum on Business Development in Mexico,

where she presented a white paper on development assistance training. Following that, Therese was involved in the 2002 Shell Livewire program, after she had an idea for a business focussed on a personalised health service. Her business plan was regarded highly enough to win her a place in the Queensland state finals, and Therese subsequently started a successful dietetic practice.

Therese completed her PhD research in the area of nutrition and diabetes prevention, in conjunction with Queensland University of Technology and the Royal Women’s Hospital in Brisbane, before moving to Perth to work at the Telethon Institute in mid-2007.

“My research project investigated the type and amount of carbohydrate with diabetes risk in older women. A highlight for me was being named the DAA Emerging Researcher for 2009 for that work,” Therese explains.

Aiming to gain further experience in student supervision and teaching, in 2010 Therese will be teaching a nutrition unit at Edith Cowan University. She is also supervising an Honours student, Susan Woolley, on a project looking at fructose intake (a type of carbohydrate) in the Raine Study.

In such a broad field as nutrition, Therese finds sometimes results can be too much of a good thing.

“The most difficult thing I find about research is trying to stay on track – there are often very interesting diversions to be found when looking at data!” she says.

An Accredited Practising Dietitian, Therese loves cooking and experimenting in the kitchen.

“Food is something to be enjoyed but there needs to be a healthy balance and variety. I like to change recipes to make healthier dishes and baked goods, and also enjoy trying different foods and cuisines. I am always inventing healthy cakes and muffins - which may or may not work out well!”

Therese balances her love of food with keeping active and enjoying the great lifestyle Perth has to offer, including playing touch footy and basketball and going to the beach.

Therese hopes her success to date is just the beginning of a rewarding research career. “My long term goal is to build a successful track record and gain my own funding for further nutrition research,” she says.

Josie Maxted



In her quest to improve health outcomes for Aboriginal people, Josephine Maxted has experienced more of our great state than most West Australian's would hope to see in a lifetime.

From Kununurra to Albany, Derby, Kalgoorlie, Warburton and most places in between, Josie's 30-year career in public health has taken her to the very outskirts of regional communities.

"In the East Kimberly area I travelled to all the remote communities, to provide education and training, clinical support, counselling and community development services," Josie explains.

Josie's work not only serviced remote communities, but also informed mining companies' human resources policies - assessing their field workers and advising safety officers on how best to work with their employees to implement strategies in dealing with drug and alcohol issues.

"I focussed energies not on just drinking, but also on the injecting of drugs, as this is a priority in the field," she says.

Josie joined the Institute in September 2009 as a Research Officer involved mainly in the Strong Foundations, Sustainable Futures partnership with Rio Tinto. The Rio Tinto Aboriginal Health Partnership, which commenced in 2008, aims to bring about improvements in the area of Aboriginal child and maternal health by addressing training, development and support needs of Aboriginal Health Workers in three key regions in Western Australia - Karratha, Roebourne and Tom Price in the Pilbara; Kununurra and surrounds in the East Kimberly; and Kwinana in the south metropolitan area of Perth.

"Over the years I have found that research plays a large part in changing policy and practices, this focussed my direction in being able to apply good research and follow this up with changes that need to be made," Josie says.

Josie is currently registered with the Australian Association of Social Workers and is highly involved in a number of State and National social work boards and committees, including the national Aboriginal Social Work Sub-Committee, and the Indigenous Social Work (WA) Meetings.

"I sit on different boards and committees as a community member and currently I am the Chairperson for Yorgum Aboriginal Counselling Service which focus their work on domestic violence, sexual assault, link up service,

Grandmother's group and community development," Josie says.

Josie's career began as an enrolled nurse in the Kimberly region in 1974 and she continued working across public sector health in hospitals, community health, geriatric nursing, community development and social work, specialising in addictions.

"I eventually went on to achieve a Bachelor of Social Work and in 1992, I won the inaugural National Captain Reginald Saunders Scholarship to study addictions in Social Work," Josie says.

Having occupied many roles in health over the past 30 years, Josie has worked for a variety of health delivery services, from the Department of the Attorney General (Victim Support Services), to Derby Regional Hospital and the Drug and Alcohol Office, to name just a few.

"My passion regarding work is the ability to be able to deliver a professional service, uplift people's lives and provide a caring humanitarian and just service for all," Josie says.

While achieving success in her career has been very rewarding to date, Josie really treasures spending time with her family.

"I try and provide my family with a role model, support, love and home life. I have three wonderful daughters who have given me five wonderful grandchildren (four boys, one girl). I would like to see that they don't want for much, but they are the captains of their destiny and make the right choices in life," she explains.

Josie is a strong advocate of further education and is looking forward to studying the addictions area in greater depth.

"I have been accepted to study a Masters in Public Health at Deakin University and would like to do research in the area of addictions as it is an area that I enjoy working in," she says.

As well as further study on the horizon, Josie is still keen to see more of Australia.

"My father comes from the Kimberly area of Broome (Yawru) and my mother from the Northern Territory region of Darwin - she was a Larrakia Nation person," explains Josie.

"My goal is to eventually buy a recreational vehicle and travel around the country applying education and training to Aboriginal communities/organisations based on what they need," Josie says.

Aboriginal Collaborative Council Advising Research and Evaluation

The Aboriginal Collaborative Council Advising Research and Evaluation (ACCARE), a committee of the Institute's Board, was formed in 2008 to provide support and direction to Aboriginal research conducted through the Telethon Institute for Child Health Research. The Council comprises a group of professional, passionate people committed to assist Aboriginal people and the Aboriginal community at large through research.

The goal and over-arching principles for the work of the Council is to ensure the facilitation, translation and application of research findings into policy and practice to improve health and wellbeing outcomes for Aboriginal families.

ACCARE provides:

- A forum for state-wide representation and consultation and dissemination of information as a result of Aboriginal research conducted by the Institute
- A focal point for advocacy for Aboriginal issues deriving from research and researchers at the Institute
- Advice on and support for effective communication and dissemination of information on Aboriginal research and research findings relevant to policy and service delivery for Aboriginal children, families and communities
- A forum to actively identify, support and foster new research opportunities for Aboriginal research and Aboriginal researchers
- Advice to the Institute on Aboriginal research priorities
- Assistance in maintaining existing collaborations with local and regional committees and organisations
- New opportunities for partnering with key external organisations or networks.

Membership of the Council is well represented across Western Australia by a strong contingent of Aboriginal and non-Aboriginal people through their involvement in the health sector and as representatives of the Aboriginal community. The Council is chaired by Rhonda Marriott, the Faculty Dean of Health Sciences at Murdoch University who also sits on the Institute Board of Directors. Dot Henry is Deputy Chair of ACCARE and is also a representative on Institute's Consumer and Participation Advisory Council.

The Council has worked hard since its inception to identify ways in which research can make the most difference for Aboriginal children and their families. It is the Institute's hope that through the expertise and involvement of ACCARE members, the Council will ensure that the research conducted at the Institute will meet Aboriginal research priorities and ensure that Aboriginal people are involved in all phases of research.

Members of ACCARE: Rhonda Marriott (Chair), Heather D'Antoine, Maude Walsh, Glenn Pearson, Dawn Bessarab and Lesley-Anne Conway.



Liz Milne



The opportunity to prevent unnecessary suffering and give children the best chance of a healthy start to life inspired Liz Milne to take up a career in cancer epidemiology. It's a move which has provided rewarding opportunities to lead further research into the causes of childhood cancer.

Since joining the Institute in 2001, Liz and her team have been pioneering research in this field, putting Australia on the epidemiological research map in terms of the causes of childhood cancers and building vital international collaborations.

"There was an active program of laboratory research into childhood cancer at the Institute but no epidemiological research into environmental, dietary or genetic risk factors. I had started my epidemiological career in cancer epidemiology and could see there was a need to do more to find out what causes childhood cancers," Liz explains.

After a 14-year career as a physiotherapist in private practice both in Perth and London, Liz completed a Masters Degree in Public Health in 1997 and then a PhD in Epidemiology in 2001.

"My original research for my MPH and PhD was about intervening in childhood to prevent skin cancer in adulthood, so the opportunity that arose for me at the Institute was a perfect fit," she says.

Liz's role at the Institute involves developing, managing and directing a program of research into the causes of cancer and leukaemia in children.

"I wanted to embark on research to try and make a difference in the 'big picture' of health, rather than continuing to work with individual patients.

"A real highlight so far has been successfully conducting three national case-control studies in collaboration with multidisciplinary research groups. These include studies of leukaemia, brain tumours and rare embryonal tumours," Liz says.

One of these studies is the Australian Study of Causes of Acute Lymphoblastic Leukaemia in Children (AusALL). The aim of this study is to determine the causes of childhood leukaemia and how it may be prevented. Previous research suggested it was related to diet, exposure to some chemicals and genetic factors. AusALL is the first to look at all these factors together.

"I am keen to analyse these data to find out whether any of the environmental risk factors we have studied are related to

the risk of ALL. Also, we want to find out whether any of them 'interact' with genetic factors to increase or decrease risk," Liz explains.

"It's very important to analyse our data and publish our findings as soon as possible, so that we can get the results into the public domain and provide feedback to the people who have taken the time to participate in our research studies," Liz says.

Liz and her colleagues are also researching the effect that a lack of key nutrients in the diet of children may have on the health of their DNA.

"This study will assess the role that diet plays in maintaining healthy DNA in children. It will hopefully tell us whether the foods children eat affect their DNA, and what can be done to maintain healthy DNA. We are also studying factors that may damage DNA in children, such as recent illness, X-Rays, exposure to chemicals in the environment and stress."

Within the Population Sciences Division, Liz also contributes to management and strategic planning. As an experienced team player, she also does her part to reduce Institute parking congestion by cycling to work every day.

When not at work, Liz enjoys travelling, skiing, hiking and generally spending time outdoors – especially by the ocean or in the bush.

Liz finds the complexities of modern life often prove challenging for families invited to take part in population research.

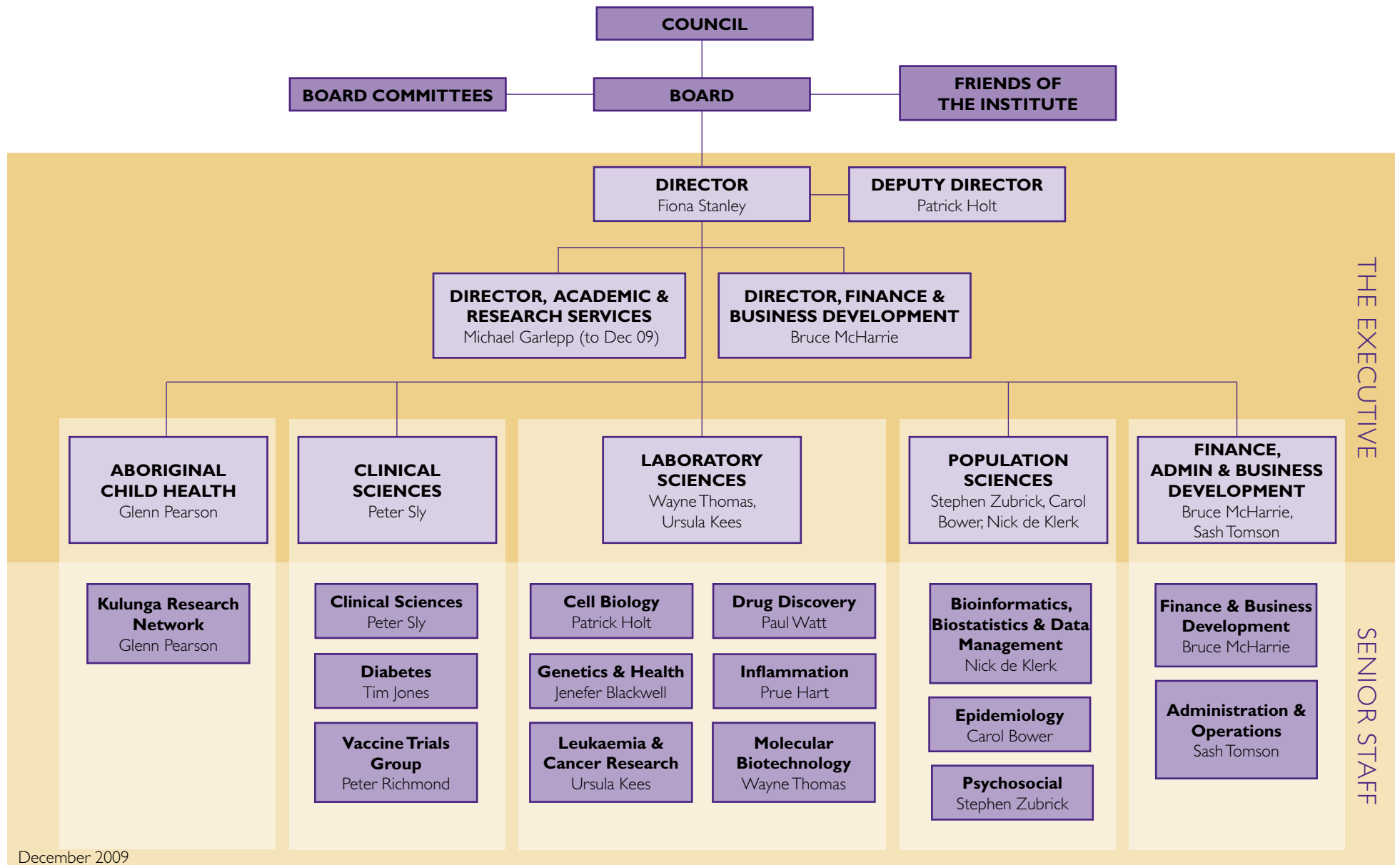
"It is a real challenge getting the message across to busy families that their participation in health and medical research is crucial to its success - people are so busy these days - it is getting harder to recruit them to studies," she says.

In terms of both inspiration and guidance throughout her career, Liz names internationally renowned cancer epidemiologists Professor Dallas English, who supervised her PhD, and Professor Bruce Armstrong who she works with closely on her cancer epidemiology studies, as well as Institute colleagues Professors Carol Bower and Nick de Klerk.

Liz's mantra "If something is worth doing, it's worth doing well" will no doubt be the key to her achieving her long term professional goal of identifying modifiable risk factors for childhood cancer, that in turn could lead to successful prevention.



Management/Operating structure



December 2009

Anke van Eekelen

Understanding the workings of the teenage mind is a universal subject that confounds parents and policy makers alike, which is exactly what drives Anke van Eekelen in her research on stress in the adolescent brain.

A Research Fellow at the Institute, Anke manages the Developmental Neuroscience Group and in collaboration with colleagues Dr Eugen Mattes and Associate Professor Jonathan Foster, coordinates the neuroscience project within the Raine Study and the Peel Child Health Study. The Stress and Adolescent Brain Maturation project specifically looks at an individual's ability to cope with stress and its relation to how well the structure and function of the brain develops during childhood and matures in late teenage years.

Anke has a longstanding interest in the biology of stress. At the University of Utrecht, she completed a Masters of Science degree immediately followed by a four year PhD, as is the tradition at any university in the Netherlands.

"During two postdoctoral periods at the Karolinska Institute in Stockholm and the University of Leiden in the Netherlands, I continued my research focussed on the neuroendocrine and molecular biology aspects of stress hormone influences on brain development and function," Anke explains.

Anke and her family are well-travelled, having relocated to Brunei and Norway before settling in Australia at the end of 2000.

"My husband and I have lived in several parts of the world, we love travelling and enjoy the experience of being in different cultures. Our children have adapted well to this lifestyle and as often as we can, we organise trips to see more of Australia and beyond," she says.

Joining the Institute in April 2001, Anke was able to resume her research interest in the biology of stress.

Early on in her career, Anke was part of the research team in the Netherlands that formulated a new theory on how a range of stress hormone effects on the brain could be explained by the presence of two different steroid receptors for the same stress hormone, cortisol.

"I find it incredibly exciting to have reached a point now, where I start using the knowledge around this concept, gained from extensive investigations over the years in animal models, in a

normal population study. It feels like a highlight in my research to have become a basic neuroscientist in a population sciences division," Anke says.

"What we believe most strongly determines either resilience or vulnerability to the impact of stress on mental and physical health is driven by genetic variation in the human population, different early life experiences and varying environmental influences on childhood development," Anke explains.

The Raine Study participants provided an ideal group to investigate the effects of life stress on adolescent brain maturation, because of the relevant longitudinal data and age of the cohort. With support of National Health & Medical Research Council funding, the research team is now focussed on analysis of the data and ensuring the outcomes will be published. Anke's goal for 2010 is to coordinate this process of data interpretation and manuscript writing.

"I was very lucky to be able to propose biological sampling of blood and saliva for extensive stress hormone analysis in this valuable cohort of our Institute. This biological approach to stress and adaptation, forms the foundation of my research effort to understand better how childhood development shapes long term stress physiology and brain function," Anke says.

Anke feels very fortunate to have a wonderful family of her own and tries hard to guide her three children through their childhood and adolescence, with a positive but realistic outlook on life, an appreciation of their overall wellbeing, hand in hand with an awareness of unlucky situations for others.

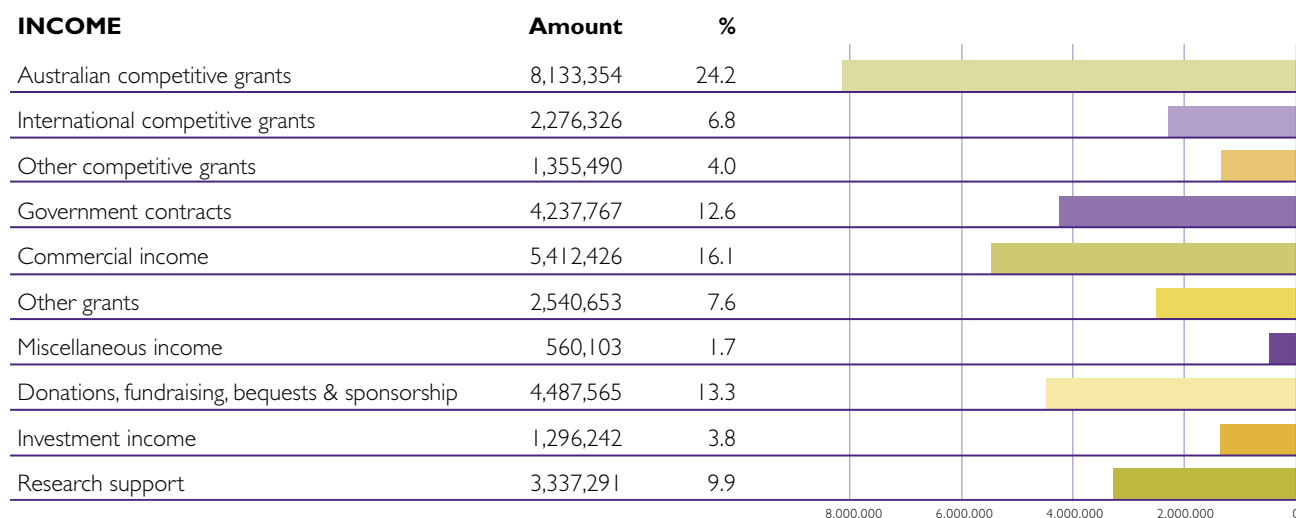
Anke's long-term research goal is to complete a profile of stress adaptiveness for each adolescent Raine participant still actively involved in the study.

"In no other prospective cohort study has such a detailed profile been established and I anticipate that we will be among the few able to study whether aspects of such a profile could serve as a risk indicator for the development of adult onset disease.

To study the impact of stress and to better understand why some of us are resilient to adverse experiences and others are unable to cope, hopefully allows me to contribute to shape better environments for children of the future to grow up in," Anke says.

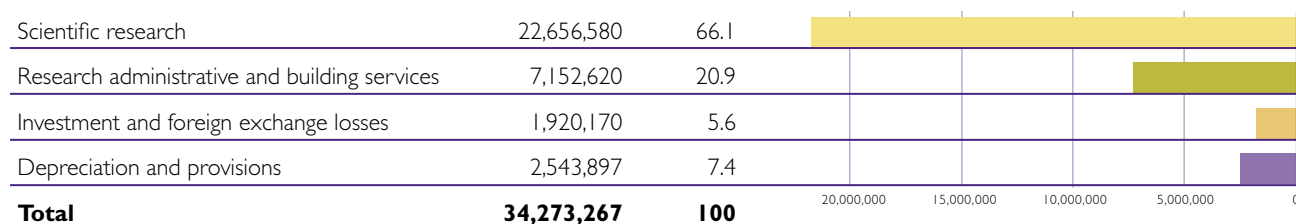


2009 - The year in brief



Gross income	33,637,217	100
Deferred income	(798,801)	
Net Income	32,838,416	

EXPENSES



PROFIT (LOSS)	(1,434,851)
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Staff and students

Total number of staff as at December 31 (paid and seconded) - 377

An increase of 2.4% (up from 368) in 2008

Total number of postgraduate students during the year - 102

An increase of 2% (up from 100) in 2008

Total staff and students in 2009 - 479

An increase of 2.3% (up from 468) in 2008

Total number of honorary and visiting scientists during the year - 90

An increase of 16.8% (up from 77) in 2008

Research income

Australian Competitive Grants			
Australian Research Council	383,699		
Australian Rotary Health Research Fund	56,608		
Cystic Fibrosis Association	43,085		
National Health and Medical Research Council	7,463,203		
National Heart Foundation Australia	186,759		
	8,133,354		
International Competitive Grants			
Autism Speaks Inc	106,774		
British Heart Foundation	53,681		
Canadian Institute for Health Research	17,851		
Cystic Fibrosis Foundation Therapeutics	189,288		
International Rett Syndrome Association	63,864		
Juvenile Diabetes Research Foundation	1,043,767		
Miscellaneous Overseas Grants	7,869		
National Institutes of Health	695,619		
Rett Syndrome Association UK	39,308		
University of Cambridge	38,840		
World Health Organization	19,465		
	2,276,326		
Other Competitive Grants			
Asthma Foundation of Western Australia	35,699		
Cancer Council Western Australia	95,804		
Child Health Research Foundation	75,805		
Children's Leukaemia and Cancer Research Foundation	623,458		
Healthway	325,087		
Melbourne Health	91,467		
Raine Foundation	90,170		
VicHealth	18,000		
	1,355,490		
Government Contracts			
Western Australia			
Department of Child Protection	101,486		
Department of Commerce	250,000		
Department of Health	2,036,919		
Department of the Attorney General	50,000		
Disability Services Commission	47,587		
Office of Science and Innovation	278,118		
Federal			
Australian Agency for International Development	189,931		
Department of Education, Employment and Workplace Relations	200,000		
Department of Families, Community Services and Indigenous Affairs	1,365		
Department of Health and Ageing	291,441		
Department of Innovation, Industry, Science and Research	730,000		
Other			
Miscellaneous - Non-WA State Governments	60,920		
	4,237,767		
Commercial Income			
Alcoa	125,000		
ALK-Abelø A/S	167,500		
Baxter Healthcare Pty Ltd	50,000		
BHP Billiton Australia Limited	137,422		
CSL Limited	742,754		
GlaxoSmithKline Australia Pty Ltd	198,577		
Merck Sharpe & Dohme (Australia) Pty Ltd	21,106		
Miscellaneous - Australian Commercial	12,196		
Phylogica Limited	1,873,270		
Pilbara Iron Company (Services) Pty Ltd	500,000		
Quintiles (Australia) Pty Ltd	80,569		
Sanofi Pasteur	39,304		
Shell Australia Pty Ltd	300,000		
Wyeth Australia Pty Ltd	342,758		
Wyeth Pharmaceuticals Inc	821,969		
	5,412,425		
Other Grants			
Australian Council of Educational Research	17,576		
Australian Paediatric Surveillance Unit	17,928		
Australian Research Alliance for Children and Youth	7,000		
Australian Respiratory Council	16,188		
Curtin University	330,572		
Edith Cowan University	11,961		
Friends of the Institute for Child Health Research	7,075		
Miscellaneous	53,472		
Murdoch University	6,745		
Murdoch Childrens Research Institute	50,691		
PMH/Women & Children's Health Service	322,459		
The Royal Children's Hospital	75,329		
The Smith Family	40,000		
The University of Technology Sydney	69,641		
The University of Western Australia	1,514,016		
	2,540,653		
Miscellaneous income	560,104		
TOTAL	24,516,119		

Our supporters

*Our supporters share our vision to give every child the best chance to a **healthy and happy future**. And that's why they support our work - because together we can make a real difference to the lives of children everywhere.*

*We would like to sincerely thank the following individuals, clubs, corporations, schools and groups for their contributions that help our scientists conduct the best research possible to enhance the **future for every child**.*

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