Research to improve the health and wellbeing of our most important asset – our children

Telethon Institute for Child Health Research

PREVENTION
INNOVATION
DEDICATION

Annual Report **2008**

Contents

Telethon Institute for Child Health Research

Who we are

The Telethon Institute for Child Health Research is Western Australia's only research facility dedicated to improving child health and wellbeing

We are housed in a purpose-built research facility on the edge of the Perth CBD and have close to 470 staff and students as well as around 80 honorary and visiting researchers throughout the year.

The Institute is a non-Government, not-for-profit organisation with strong affiliations with the State children's hospital and all the major WA universities.

The Institute is headed by Professor Fiona Stanley AC who was named 2003 Australian of the Year for her commitment to improving the health and wellbeing of Australia's young people.

What we do

Our focus is on children, young people and their families and the environments in which they live.

Our research priorities are focused on the most complex, costly and devastating health problems facing our children in the 21st century.

We have a firm commitment to promoting evidence-based action and preventative strategies.

You will find information about our broad range of research programs in the following pages.

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

Professor Fiona Stanley with Brandon and Eleanor

There's nothing like a 'Global Financial Crisis' to sharpen our thinking about what are the really important things in life. As painful and difficult as the fiscal events of late 2008 continue to be for so many, it has produced a valuable, and some would say overdue, debate over our society's priorities.

So the boom is over, and what is its legacy? For years we have been warning that our young people were not benefiting from our nation's growing affluence. In fact, as our economy soared, the factors in society that support families to nurture their children declined. A succession of reports has documented the alarming decline in the key indicators of child health and wellbeing. This paradox of progress was not unique to Australia, but could also be seen in other developed countries, particularly the US and UK. The needs of children and families were never a central consideration as we strove towards national growth. If they were, then the debates over issues like paid parental leave, junk food advertising, childcare funding and alcopops would be quite different.

Of course, we all know that a recession is not good for children and families. Those who are already disadvantaged are likely to suffer even more in the tough times ahead. This debate is not about the accumulation of

wealth, but our priorities. If the health and wellbeing of our next generation is diminished, then so is our future capacity. The needs and welfare of our children must always be our top priority. I believe every government and corporate proposal and policy should not only be assessed on their cost effectiveness and environmental impact, but also on how they'll affect children and families.

Having discussed the big picture, as Director of this Institute, I am of course faced with the reality of how the global downturn will impact on our organisation. In the best of times, it is a challenge to secure appropriate funding for research. Over the years the Institute has grown a capital fund where the investment income funds extra salaries and infrastructure. With the sharp decline in investment returns, we will be appealing to our government and corporate supporters and our generous donors for their continued support. There is no doubt in my mind that we have a compelling case - research is even more important when budgets are tight to ensure that there is solid evidence on where the spending will be most effective. It also strengthens the case for investment in more preventative and early intervention strategies that have been repeatedly demonstrated to be far more cost effective – and humane – than dealing only at the crisis end of the scale.

In terms of national advocacy, I am honoured to have been invited to continue to serve on the Prime Minister's Science, Engineering and Innovation Council which provides regular advice on a range of issues to the Hon Kevin Rudd. With other Institute colleagues, I was a participant in the Government's 2020 Summit which provided a valuable opportunity for a vigorous exchange of ideas. I also have the challenging responsibility of serving on the Social Inclusion Board and the WA Government's Indigenous Implementation Board – both groups have challenging briefs to bring about substantial change to improve the lives of some of the most disadvantaged people in our society. How we fare in these two important areas reflect our priorities as a nation.

Of course all of our advocacy is underpinned by rigorous research. I am very proud that the Institute has again been awarded a major program grant from the National Health and Medical Research Council to undertake a substantial and innovative body of work relating to the social determinants of health and wellbeing in our children. This is the type of research that will really assist in our understanding of the very broad factors that impact on child health and development. At the same time our research teams in asthma and allergy, cancer and leukaemia and infectious diseases continue to publish at the cutting edge of their fields. We are very fortunate to have recruited two outstanding additional bioinformaticians who work across our divisions to support the very complex analyses that are required.

The documentary 'Risking Our Kids' was a wonderful opportunity to showcase our Institute and I am indebted to film maker Jennifer Lee Lewes and the teams at RymerChilds and Thunderbox Productions for their passion, dedication and sensitivity. The film, which highlighted the declining trends in many child health indicators, was broadcast in prime time on the ABC and prompted enormous feedback and support for our work.

We remain indebted to the people of Western Australia for their support. So many families participate in our trials and studies - a commitment that often continues over many years. The Friends of the Institute is a very active group and run a number of events to raise funds to support our research activities. There are dozens more volunteers who serve on our Scientific and Consumer Councils.

We are very grateful for the continued support of Channel 7's Telethon which underpins so much of our activities. Telethon holds a special place in the hearts of West Australians and we are honoured to be a major beneficiary.

As Director, I have very much appreciated the guidance of our new Chairman, Mr John Langoulant, who brings enormous experience to that role. We have also welcomed Professor Anne Kelso and Mr Michael Manford onto the Board. Both of these new Board members bring very high level skills from their own sectors that add real value to our considerations.

It is with some sadness that we have farewelled this year one of my most valued colleagues and friends, Bob Ginbey, as he headed into retirement. As head of Administration and Corporate Services, Bob was responsible for setting up many of the systems and groups within the Institute. He always provides great counsel and the best flow charts! We wish him and his wife Marie the best of times in this new phase of their lives.

Finally, I want to thank and acknowledge our extraordinary staff. From the senior scientists to our wonderful bunch of post-graduate students and dedicated administrative staff, I continue to be overwhelmed by their commitment and enthusiasm for the task at hand. We all share a very special bond, knowing that while our work is challenging, it is very important and will make a difference to the lives of many.

Fiona Stanley AC

2008 Highlights

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

In 2008, Institute researchers were recognised for their research outputs, their high-level advocacy and their impact on policy.

John Langoulant appointed Chairman of Institute Board

Business leader Mr John Langoulant was appointed Chairman of the Board of the Institute following Mr Kevin Campbell's decision to step down as Chairman after fourteen years in the position. Mr Langoulant is the CEO of Australian Capital Equity and is a Senate Member of The University of Western Australia. The Board was also boosted by the appointment of Professor Anne Kelso from Melbourne, Director of the World Health Organisation Collaborating Centre for Reference and Research on Influenza and an internationally respected immunologist. Mr Michael Manford, Executive Chairman and CEO of Paterson Securities Limited also joined the Board in 2008. Mr Graham Mitchell, Principal of Foursight, retired from the Board after eight years of service.

International award for Rett syndrome research

The Institute's Dr Helen Leonard received the 2008 *'Circle of Angels Research Award'* from the International Rett Syndrome Foundation for her substantial contributions which have not only increased the understanding of Rett syndrome but have helped define the Rett syndrome phenotype and clinical outcomes. The Award also recognised Helen's collaborative involvement with the InterRett Database, a critical resource for researchers, clinicians and families.

'Risking Our Kids' documentary

Professor Fiona Stanley and the Institute were the subjects of a documentary called '*Risking Our Kids*' which aired on ABC TV on October 7, 2008. See page 47 for a feature report on the film.

Award for highly cited researcher

Professor Pat Holt, Head of our Division of Cell Biology and Deputy Director, was one of eight UWA researchers to be recognised as a highly cited researcher. The highly cited list is compiled by Thomson ISI and recognises researchers whose work is exceptionally highly cited in the international literature. Over his career spanning four decades, Professor Holt has published over 450 papers in high-quality peer-reviewed journals and is one of the world leaders in research into the immunology of asthma and allergy.

Australia 2020 Summit

The Institute was represented at the Australia 2020 Summit by a number of staff including Professor Fiona Stanley, Professor Colleen Hayward, Adele Cox and Dr Christine Jeffries-Stokes as well as Board member Dr Jackie Huggins. The Summit was an exciting initiative aimed at harnessing the best ideas for building a modern Australia ready for the challenges of the 21st century.

Links between passive smoking and recurrent ear infections

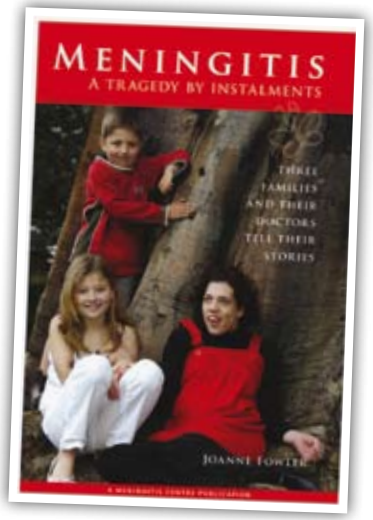
Two hundred and eighty families in the Kalgoorlie-Boulder area of WA participated in an Institute study which found a strong link between childhood ear infections and exposure to tobacco smoke. The research results were published in the *Medical Journal of Australia*.

Inaugural Consumer and Community Participation Symposium

Along with the UWA School of Population Health, the Institute hosted the inaugural *Involving People in Research Symposium*. The Symposium attracted speakers and attendees from around Australia and the world and provided a forum for people to explore important issues and discuss future plans and directions for consumer and community participation in health and medical research.

Meningitis: A tragedy by instalments

The Meningitis Centre at the Institute launched a new book to raise awareness of meningitis. Entitled *'Meningitis: A tragedy by instalments'*, the book tells the stories of three families and their doctors who have been affected by the disease. For more information visit www.meningitis.com.au



Swimming pools are cool!

A report looking at the health impacts of swimming pools in two remote Aboriginal communities was published in the *Medical Journal of Australia*. The study found that in the seven years following the installation of the pools, infections including respiratory, skin and middle ear infections were more than halved and there was an associated drop in antibiotic prescriptions. These results are particularly important as Aboriginal children suffer very high infection rates compared to the rest of the community which can go on to have lifelong adverse effects on their health.

Fiona the Blogger!

Our Director Professor Fiona Stanley became a blogger in 2008. A blog (short for 'weblog') is a frequently updated, personal website featuring diary-type commentary and links to articles on other websites. Professor Stanley contributed

2008 Highlights

weekly blogs to the *WA Today* website on topical issues such as child abuse, obesity, vaccination and her dinner with US Secretary of State Condoleezza Rice.

'*Life at 3*' documentary

'*Life at 3*' was a two-episode documentary forming the second part of the 'Life' series examining the growth and development of a group of children from birth. It was screened on ABC TV in October 2008 and featured the Institute's Professor Steve Zubrick. The *Life* series was made in conjunction with a long-term study - The Longitudinal Study of Australian Children (Growing Up in Australia) led by the Australian Institute of Family Studies (AIFS) - in which 10,000 children are being studied from both a sociological and scientific viewpoint. The *Life* families are pictured below.

New approach needed for child abuse prevention

A paper co-authored by several Institute researchers highlighted the need for improved ways to tackle the growing problem of child abuse. Australia is seeing an unprecedented increase in the rate of child protection notifications and children being taken into care – doubling in the past decade – which requires a new approach of preventing the abuse in the first instance rather than the current focus on intervening once harm has already been done.

Telethon 2008

Channel 7 Perth's Telethon 2008 was a huge success raising a record total of $7,535,678 for the children of Western Australia. The Institute is a major beneficiary of Telethon, along with many other WA children's charities. For the Institute, a highlight of the weekend was our display booth at the Perth Convention Exhibition Centre giving us the opportunity to meet families and tell them about our research. Our most grateful thanks to Channel 7 and everyone who contributed to Telethon 2008.

'Flu vaccine trial

Our Vaccine Trials Group began a trial looking at the effectiveness of the current vaccine to target influenza. Part of a nation-wide study, the trial will assess just how effective the 'flu vaccine is in preventing the disease, with 319 West Australian adults aged 18 to 64 years recruited to the study.

Award for Suicide Prevention

The Ministerial Council for Suicide Prevention, which is based at the Institute, won the 2008 LiFE Public Sector Award from Suicide Prevention Australia. The Award recognised special contribution and achievement to supporting community, business, industry, research and the service sector in promoting awareness, education and information on suicide and suicide prevention.

2008 NAIDOC Person of the Year

Professor Colleen Hayward, Manager of the Institute's Kulunga Research Network, was named 2008 National NAIDOC Person of the Year. This award is a significant achievement in recognising Colleen's long-standing work for and on behalf of the Aboriginal and Torres Strait Islander communities across Australia.

Consumer involvement recognised

Institute researchers Jan Payne and Heather D'Antoine, from the Alcohol and Pregnancy Project, received a Health Consumers' Council Excellence Award for their outstanding contribution to consumer and community participation. The consumer and community participation aspects of their alcohol and pregnancy project were an example of 'good practice' for community engagement and included community reference groups that consisted of consumer and community representatives from both Indigenous and non-Indigenous backgrounds. Jan Payne is pictured below (centre) with Consumer Representatives Pip Brennan and Jess Braithwaite.

John Lillie Fellowships

Dr Peter Dallas and Dr Nick Gottardo were appointed John Lillie Cancer Research Fellows by the Institute. The opportunity for the Lillie Fellowships followed a bequest from the Late John Lillie to allow for the continuation and expansion of the Institute's high quality childhood cancer research. The bequest was matched by a contribution from The University of Western Australia.

Stress in pregnancy study

Our researchers have published data from a study showing that children whose mothers were stressed during pregnancy are at higher risk of developing behavioural and emotional problems. The analysis found that maternal smoking, low income during pregnancy, multiple 'baby blues' symptoms after birth and stress were each associated with poorer behavioural and emotional outcomes in preschool children.

Professor Stanley presents the Annual Hawke Lecture

The Annual Hawke Lecture is the premier national event on the public calendar of the University of South Australia, delivered under the auspices of the Bob Hawke Prime Ministerial Centre. Professor Stanley delivered the 2008 lecture and addressed the issue of the poor state of health of Australia's Indigenous population and the country's failures to induce change.

2008 QANTAS Young Investigator Award

PhD student Conny Bertram was the 2008 winner of the annual QANTAS New Investigator Award for her research into paediatric brain tumours. Conny's research involves analysis of the genes that are functioning abnormally in brain tumours and examining tumour cells derived from patients to help understand how these tumours develop and provide targets for potential new therapies. With her award, Conny will attend an international research meeting in Spain, and visit leading brain tumour research centres in the US and Canada. Conny is pictured below with Ian Gay from QANTAS and Professor Fiona Stanley.

Accolades for our Director

Congratulations to our inspiring Director, Professor Fiona Stanley, for winning the Australian Medical Association's (AMA) highest award. Professor Stanley won the AMA's Gold Medal for 2008 for her outstanding contribution to medicine, medical research and child health. Professor Stanley was also honoured in the 6th Annual '*Thank You Day*' Awards, receiving the 2008 Bupa Australia Leadership and Innovation Award as recognition for her exceptional leadership towards making health and medical research a higher national priority. She also took part in the Australian Leg of the Olympic Torch Relay leading up to the 2008 Summer Olympics in Beijing, China. In December 2008, Professor Stanley was awarded an honorary Doctor of Medicine degree from The University of Melbourne.

Meet the Bioinformatics team

Kim Carter, Nick de Klerk and Richard Francis

Bioinformatics is definitively the new buzz word in medical research, despite the term being originally coined over 30 years ago.

Back then, Paulien Hogeweg, a Dutch theoretical biologist and complex systems researcher, used it to describe 'the study of informatic processes in biotic systems.'

Nowadays, 'bioinformatics' in broad terms encompasses the branch of life science that applies information technology to the field of biology to help understand various biological processes.

It's all about data, and lots of it.

For a number of years, Institute researchers have been using microarray technology to rapidly screen thousands of genes at the same time.

These microarray experiments take a snapshot of every gene in a particular cell or tissue and measure their expression levels, in some cases generating data for over 20,000 different genes.

It's important information that helps us to study a range of different childhood diseases, including asthma and allergy, leukaemia and brain tumours.

But the challenge has been to combine this vast amount of biological data so that researchers can form a comprehensive picture which may help to unlock why, for example, some cells become cancerous or why the immune cells from allergic people hyper-react to harmless proteins.

The arrival of Professor Jenefer Blackwell's Genetics and Health team from Cambridge

in 2007 heralded the beginning of another group of researchers collecting vast amounts of data.

One of the Genetics and Health team's research interests is to use large-scale family-based genome-wide association studies to look at the causes of a number of infectious diseases including *leishmaniasis* and otitis media (middle-ear infections).

Information is collected from populations as far as Brazil, Sudan and India as well as from here in Western Australia.

Like the microarray experiments, the huge amount of data generated in these studies has proven a challenge to not only collate and store but also to analyse in order to work out which results may be biologically significant.

Professor Nick de Klerk, Head of Biostatistics and Genetic Epidemiology, explains that after consultation with senior researchers in mid-2007, the wheels were set in motion to recruit and develop a specialised bioinformatics team to assist in the management of the data sets generated by these studies.

"We got to a point where we had the samples, the technology and the expertise to generate an amazing amount of valuable data, but we were lacking the capacity to efficiently store and analyse it to get the most possible out of what had been collected," says Nick.

"The development of a team devoted to this task seemed like the obvious next step in progressing the research at the Institute."

So in early 2008, with funding from the State Government's Centres of Excellence program, bioinformaticians Dr Kim Carter and Richard Francis were recruited into Senior Bioinformaticians positions at the Institute.

Prior to joining the Institute, Kim had contributed a number of significant informatics tools to the bioinformatics and wider research communities that have generated national and international interest and are being used by research groups across the world.

"One of the things I'm really passionate about is improving the recognition of the field of bioinformatics," says Kim.

"In each of the roles in my research career to date, I've tried to build and develop the relatively scarce human capacity within the field by collaboration, seminars and supervision and mentoring of students and so I jumped at the opportunity to continue this at the Institute."

Richard Francis, a bioinformatician working at the Cambridge Institute for Medical Research (CIMR), was enticed to leave the green pastures of England for the sunny shores of Australia by the promise of an exciting career opportunity at the Institute.

"During my time at the CIMR, I had a dual position in that I set up the Institute's bioinformatics facility from scratch and provided a bioinformatics support service for the building," explains Richard.

"Whilst I thoroughly enjoyed my six years there, I was ready for a change and the opportunity to move to Australia came at the perfect time, even though it was a slightly scary prospect!"

Richard and Kim are now jointly leading and developing a program of bioinformatics at the Institute, under the supervision of Professor de Klerk.

The majority of their work to date has been focussed in the Divisions of Genetics and Health, and Leukaemia and Cancer Research.

However, other divisions are beginning to utilise their services in managing a number of the large population-based studies being undertaken.

"As bioinformaticians, Richard and I provide a core bioinformatics service to all research divisions, which essentially involves collaborating with researchers to enable them to better use computer technologies to improve research outcomes," explains Kim.

Adds Richard: "It's our job to design the databases to store the data efficiently, work with the biostatisticians when required to analyse the data effectively and develop the visualisation tools to allow researchers to more easily pull out the patterns in their data."

Despite its rapidly emerging importance, the world of bioinformatics is still rather enigmatic to the majority of the staff at the Institute.

Both Kim and Richard agree that the team's main goal is to educate fellow Institute researchers on the advantages of utilising the services that they offer.

Says Kim: "We've still got a bit of setting up to do to get a fully comprehensive service running, so as a short term goal I'd have to say getting more of a presence in the building and increasing our usage and capacity is a definite aim. In the long term, I would love to see the development of a large group of bioinformaticians based at the Institute who are dedicated to improving child health and child health research."

While both admit that they are passionate about their work, in their spare time Kim and Richard indulge in their other hobbies.

For Kim, that involves hockey (he plays for Curtin Trinity Pirates), beach volleyball and dabbling in the garden.

Sport also plays a big part in Richard's life, and Australia has introduced him to a couple of new ones.

"I love sport of any kind," says Richard. "It doesn't matter what it is, who's playing or where, I'll watch it! I'll also try my hand at anything new given the opportunity and I'm mad keen on getting into kite surfing next year.

"I also want to get back in to football (soccer) so if anyone needs new recruits for their team then give me a buzz!"

Chairman's message

The Board has had a strong focus throughout the past year on ensuring the Institute has both the financial and human resources needed to continue to build on its impressive track record.

This has not been without challenge. The Board has been particularly conscious of a growing disparity between the salary levels at the Institute compared with the Australian university sector. This has arisen over recent years as the university sector has moved to top-up salaries, spurred on by fierce competition within that market.

There is no question that investing in our staff should be our top priority. Therefore, we took the decision to implement a two-year plan from January 2009 whereby the Institute will supplement, from its own resources, the salaries of those employees who are paid according to the Institute salary classification levels. The cumulative effect of this series of increases is an increase of 18 per cent, which will go a considerable way towards closing the salary gap and achieving the overall objective of parity in three to four years.

The downside of this action is that it does draw on the Institute's accumulated capital and reduces our ability to fund other initiatives such as strategic recruitments and equipment. It also reveals the fundamental inadequacy in the way research is funded at a national level. While grants from the National Health and Medical Research Council are our primary source of research income, the salary component is clearly below market rates. Another frustration is that the grants only fund the salary component and do not contribute towards the equipment and ancillary services that are needed to carry out the research. We continue to lobby for a review of this system to ensure greater fairness and a better reflection of the true cost of research.

The Institute also receives vital funding from the Western Australian Government's Medical Health and Research Infrastructure Fund (MHRIF). These funds are essential to the Institute's continued viability and are allocated according to research success. However, it is of considerable concern that this fund has been declining in real terms despite the demonstrated increase in our research outputs. We will continue to pursue vigorously with the State Government the retention and growth in real terms of the MHRIF.

The Board is naturally very conscious of the impact of the economic downturn in reducing investment income and other sources of funds required to provide the services needed for research and to run the Institute. The Finance and Corporate Governance Committee will develop a three-year strategy to address the pressures from declining infrastructure income and increasing costs. I extend our appreciation to our financial advisers, JANA, for their careful investment advice in these difficult times.

Another key consideration for the Board is the Institute's building program. The State Government's commitment to build a new children's hospital on the QEII campus by 2014 has major implications for the Institute. As an organisation, we are committed to remaining co-located with the children's hospital to enable the best possible synergies between the research environment and the bedside. We are actively involved in the planning of the QEII campus and the identification of an appropriate site for the Institute's future relocation. While the move presents an exciting opportunity to develop an integrated medical research and education hub on the new campus, it presents a major challenge in raising sufficient funds to build a suitable building. In the meantime, the pressures on our current space require careful management.

The cumulative effect of these developments further highlights the need for the Institute to continue to engage philanthropic and corporate support. Considerable efforts are being made to increase funding in both areas. The Board is committed to continuing to build the long-term relationship between Channel 7's Telethon and the Institute. We remain indebted to the ongoing support of the Telethon Trustees and, in particular, the personal support of the Chairman of both Channel 7 and Australian Capital Equity, Mr Kerry Stokes AC.

As the new Chairman of the Board, I would like to recognise the enormous contribution of Mr Kevin Campbell AM, who served in this position from mid-1994 for a period of 14 years. Kevin's steady stewardship over that period has resulted in the Institute being very well placed to address the range of challenges that are now before us. He was a well-deserving recipient of Life Membership of the Institute in May 2008.

I would also like to acknowledge Professor Lou Landau who stepped down from the Board in May 2009 after more than 20 years of service to the Institute including the role of Board Chairman in the early years, and Chair of the Scientific Advisory Committee. Professor Graham Mitchell AO also made a very significant contribution to the Board before stepping down during 2008. I would like to warmly welcome Professor Anne Kelso AO and Mr Michael Manford who both joined the Board in 2008 and bring with them an impressive and diverse range of experience. I am grateful to the entire Board and all Board Committee members for their ongoing commitment to the future of this Institute.

I would also like to recognise the enormous contribution of Mr Bob Ginbey to the Institute. Bob retired after 14 years with the institute as its Head of Administration and Corporate Services. We wish him well for the retirement phase of his life.

Finally I would like to congratulate Professor Fiona Stanley AC and her Institute staff and students for their outstanding achievements in 2008. I am very pleased to see the Institute continue to grow in both size and reputation. The Board is committed to supporting that success in every way possible. We look forward to working together to bring real improvements to the health and wellbeing of children in Australian and around the world.

John Langoulant

Board of Directors

The Board of Directors manages 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, Australian Capital Equity Pty Ltd; Member, Senate of The University of Western Australia.

Jackie Huggins AM, Deputy Director, Aboriginal and Torres Strait Islander Studies Unit, University of Queensland; Co-Chair, Reconciliation Australia; Director, Telstra Foundation; Director, Australian Centre for Indigenous History, Australian National University.

Keith Jones, Board Member, Deloitte Corporate Finance Pty Ltd; Managing Partner, Deloitte Touche Tohmatsu Western Australia.

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.

Louis Landau AO, Emeritus Professor and Honorary Research Fellow, School of Paediatrics and Child Health, The University of Western Australia.

Jenni Ker, President, Friends of the Institute.

Retired in 2008 and not pictured: Kevin Campbell AM, Chair, Telethon Institute for Child Health Research (1994 - 2008); Graham Mitchell AO, Principal and Chief Executive Officer, Foursight Associates Pty Ltd.

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

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; Australian of the Year 2003.

RESEARCH PRIORITIES

What is more important – preventing children's cancer or disabilities?

Infectious diseases or birth defects?

Asthma or obesity?

Youth suicide or SIDS?

Of course they're all a priority, particularly for the families desperate for research to provide the answers and hope for their children.

That's why at the Telethon Institute for Child Health Research our focus is on the whole child, from pre-conception through the teenage years.

We know that an innovative approach is needed to tackle the increasingly complex issues affecting the health and wellbeing of children in the 21st century.

The Institute's unique, multidisciplinary approach means we tackle these issues from a range of angles. Our world class teams include geneticists, molecular and cell biologists, bioinformaticians, biostatisticians, epidemiologists, psychologists, public health researchers, clinicians and social scientists.

We have eight overarching research streams:

- Aboriginal child health
- Asthma, allergy and respiratory disease
- Cancer
- 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. We are also investigating better treatments, therapies and intervention strategies.

What is clear is that there is rarely a simple solution. The days are gone of hoping the answers would be found in a single gene or a simple pill.

So what does it take? We find answers through persistence, dedication and bringing together the right people.

It's been a formula for success at the Telethon Institute for Child Health Research - rigorous science to improve the lives of children everywhere.

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

RESEARCH PRIORITY AREA: Aboriginal child health

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

They're more likely to be born pre-term and with a lower birth weight. They suffer high rates of SIDS, infectious diseases and emotional and behavioural problems.

In partnership with Aboriginal people, the Institute is not only investigating what can be done to reduce these risks, it's also enhancing the capacity of Aboriginal researchers to undertake their own studies in areas ranging from fetal alcohol syndrome to Indigenous self esteem.

Too Solid Program

We have developed an Aboriginal-specific program for parents and carers of Aboriginal children living in Perth which is designed to improve parenting knowledge and skills, reduce social, emotional and behavioural problems in young children and assist parents in preparing children for success at school. It aims to address the intergenerational effects of past policies of forced separation of children on the cultural and social transmission of parenting knowledge and skills.

The Too Solid Program is currently being trialled in Perth and involves parents and other family carers of Aboriginal children aged three to five years. The program is comprised of seven two-hour group sessions followed by a half day concluding family celebration.

The program curriculum and materials were developed through qualitative research with Noongar elders, parents and other key stakeholders and a design team of Aboriginal and non-Aboriginal child development and parenting experts. The group sessions are delivered by trained Aboriginal facilitators and include cultural narratives and semi-structured group discussion prompted by culturally-relevant videos and a participants program manual and tip-sheets for each session.

The Too Solid sessions cover a range of topics aimed at restoring identification with culture, promoting parental confidence, knowledge and child rearing skills and enhancing resilience in Aboriginal children.

Rio Tinto Aboriginal Health Partnership

The Rio Tinto Aboriginal Health Partnership commenced in July 2008 and will continue for two years. The Partnership 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 surrounding areas in the East Kimberley; and Kwinana in the south metropolitan area of Perth.

The Partnership builds on the outcomes and relationships developed during a previous five-year partnership between Rio Tinto and the Institute which recognised the critical role Aboriginal Health Workers play in meeting the complex health care needs of Indigenous people and the range of workforce development issues faced by Aboriginal Health Workers.

This new Partnership will provide practical tools and activities to help close the gap in Aboriginal health outcomes. Community consultations have been held in Kwinana, the Kimberley and the Pilbara to identify needs and priorities and these will inform the activities which will build the skills, knowledge and capacity of Aboriginal community health workers. These activities will include: a maternal and child health toolkit, regional workshops, education scholarships, online learning, and a national Aboriginal community health worker symposium.

The Partnership is an undertaking between Rio Tinto and the Telethon Institute for Child Health Research through our Kulunga Research Network.

BHP Billiton Health Partnership

Staying on Track (managed through our Kulunga Research Network) is the second project funded through the BHP Billiton Iron Ore Health Partnership Agreement and aims to reduce substance misuse for Aboriginal young people in Hedland, Newman and surrounds.

Results from our WA Aboriginal Child Health Survey for this region show that 27 per cent of Aboriginal young people reported high levels of alcohol use and 24 per cent reported marijuana use. Issues of mental health, social and emotional wellbeing and suicide are also a concern within the region.

Our researchers have been involved in a participatory action research process working with young people and key stakeholders to identify and develop innovative preventative programs to address these issues. The community partnership in Hedland has used action research to empower young people to transform their lives and create a more socially just, caring and responsive community. An important early outcome of initial consultations to address youth issues in Hedland was the development of the Hedland Youth Stakeholder Action Group and the Hedland Youth Leadership Council. These groups ran a series of workshops and forums to identify and address a range of issues highlighted by young people including racism, marginalisation, boredom and high levels of substance use, poor education and employment outcomes.

An evaluation will be undertaken with young people to assess the effectiveness of these interventions in empowering young people, their decision-making around substance misuse and social and emotional wellbeing.

Indigenous Capacity Building Grant

In 2005, an Indigenous health research capacity building grant from the National Health and Medical Research Council was awarded jointly to the Institute, Curtin, UWA and Combined Universities Centre for Rural Health. It was the first grant of its kind comprising all Indigenous team investigators.

The research program, called *'Not Just Scholars but Leaders: Learning Circles in Indigenous Health Research'*, aims to develop a critical mass of Indigenous researchers undertaking high quality research into population health research priorities determined by Aboriginal and Torres Strait Islander people and to link research findings into policy and practice. This research will allow us to develop a better understanding of the best and most cost-effective ways of providing preventive and acute care for Indigenous Australians. The program is investigating lifestyle, behaviours and susceptibility to disease as well as factors in people's lives that influence health in a positive way.

The Indigenous team investigators supported by the grant are located in Western Australia, the Northern Territory and Queensland and include one medical doctor, two researchers who have completed doctorates and seven with Masters degrees. To date, they have had 24 publications in peer-reviewed journals and published three book chapters.

The grant aims to develop the investigators into independent lead researchers in their own right with some investigators being awarded postdoctoral fellowships, winning research grants or accepting positions in the health field.

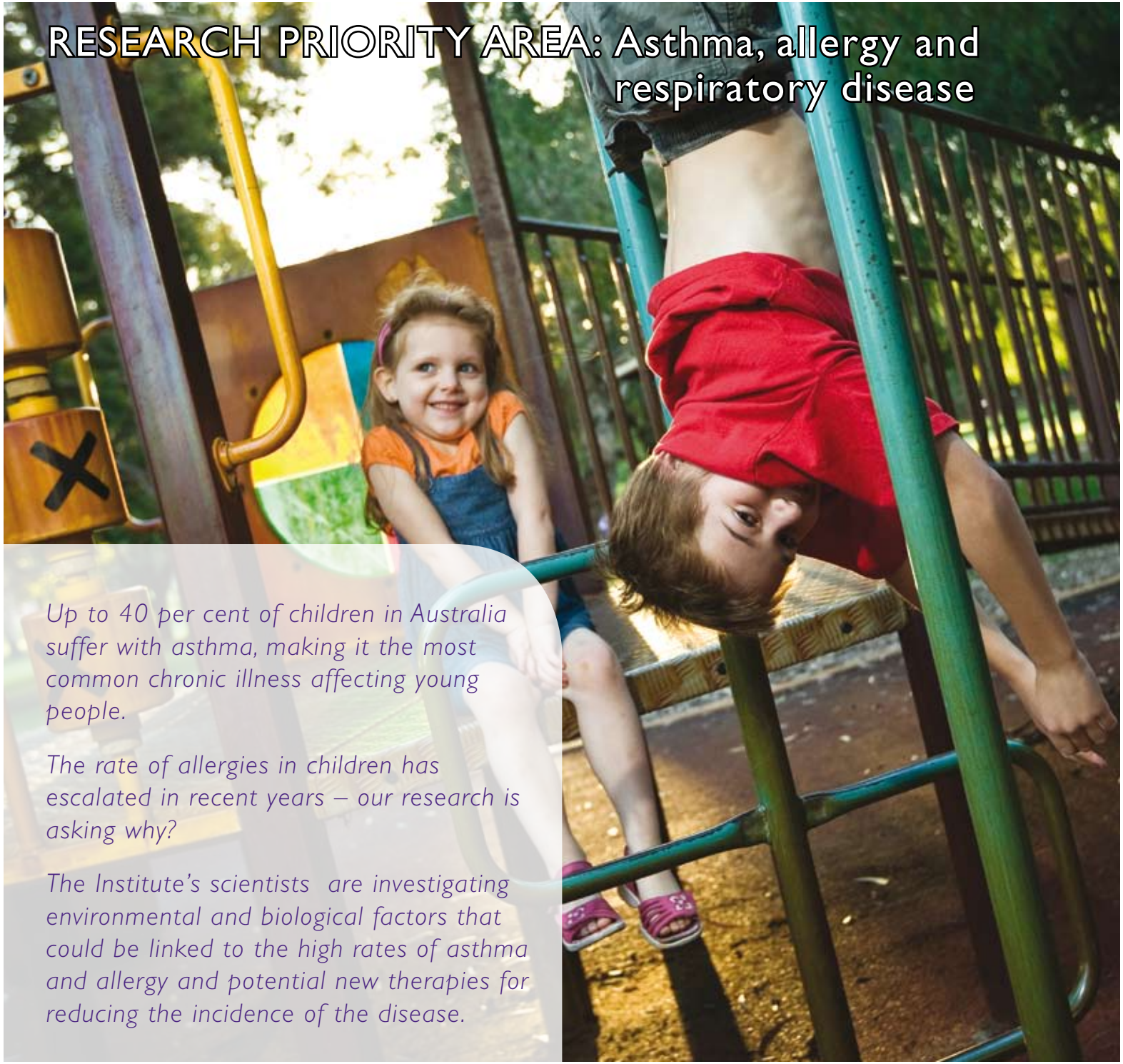
Alcoa Partnership

A new partnership between Alcoa and the Institute (through our Kulunga Research Network) commenced in January 2008 and will run until 2011. *'From the Ground Up - Working with communities in the South West'* will implement a range of targeted activities to build capacity amongst Alcoa staff and the Aboriginal communities in the Peel and South West regions of Western Australia.

The partnership complements and supports Alcoa's social investment strategy, both internationally and in Australia, which regards people as their most valuable asset, is committed to equal opportunity for women and places a particular focus on improving the lives of Indigenous people (Alcoa in Australia). The partnership also addresses the Alcoa 'Safe & Healthy Children and Families' portfolio.

From the Ground Up will encourage and support Alcoa staff to participate in cross-cultural training which will enhance their competence in promoting greater Indigenous participation in local community activities designed to promote safety and health outcomes through their active involvement and mentorship. It will also aim to develop the capacity of all children, young people, individuals and families through their engagement in existing and new community-based initiatives and develop capacity in communities by acknowledging and promoting Indigenous cultural strengths.

RESEARCH PRIORITY AREA: Asthma, allergy and respiratory disease



Up to 40 per cent of children in Australia suffer with asthma, making it the most common chronic illness affecting young people.

The rate of allergies in children has escalated in recent years – our research is asking why?

The Institute's scientists are investigating environmental and biological factors that could be linked to the high rates of asthma and allergy and potential new therapies for reducing the incidence of the disease.

AREST CF

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. The program is extremely well accepted with more than 95 per cent of eligible families participating.

The current AREST CF program consists of a comprehensive assessment soon after diagnosis (around 3 months of age) and an annual assessment until around 6 years of age. Each assessment includes measurements of inflammation and infection in the lung, lung function in infants and preschoolers and chest scans that show us detailed lung structure.

Results so far show that inflammation begins early in life and may be present even though we can't detect an infection. Infants can have lung damage and infections even though they have no apparent respiratory symptoms. Results also show that lung damage is more common than first thought in young children with 67 per cent of children having gas trapping in the first year of life and 40 per cent of children have bronchiectasis by the age of four.

The information we collect in the first few years of life will allow us to better understand which factors predict lung damage by school-age and which tests best reflect the progress of lung disease early in life.

WA Twin Child Health Study

The WA Twin Child Health Study has collected information from families of multiples born in WA between 1980 and 1992 who belonged to the WA Twin Register. The aim of the study is to examine the roles that genes and the environment play in the link between childhood asthma and allergy and exposure to environmental tobacco smoke. We have received completed questionnaires from nearly 2,500 families, resulting in data from over 13,000 individuals.

Some results from WA twin families include:

- the prevalence of asthma was higher in children (27 per cent) than in their parents (15 per cent)
- mothers had a higher rate than fathers (18 per cent vs. 12 per cent)
- in children, girls had a lower rate than boys (24 per cent vs. 30 per cent).
- no difference in asthma prevalence between twins and their siblings (28 per cent vs. 26 per cent) and between identical and non-identical twins (28 per cent vs. 27 per cent).
- the risk of asthma in twins was increased six-fold if both parents were asthmatic.

Other factors which increased the risk of asthma in twins included being male, living in the city, having no older siblings, mothers experiencing a threatened miscarriage during pregnancy, having at least one episode of otitis media during childhood, having had tonsils removed and being in the bottom 10 per cent with respect to the SEIFA indexes of disadvantage and economic resources. There was no relationship between asthma in twins and exposure to environmental tobacco smoke.

House dust mite and cat allergy

Allergy is defined as the inappropriate or exaggerated response of the immune system to harmless stimuli in the environment.

Allergies to house dust mite and domestic cats have remained the main focus of our allergy research at the Institute since they are amongst the most important causes of allergy worldwide and are especially dominant in Australia. One of the major tasks being undertaken is to decipher which of the proteins contained in the house dust mite or cat dander are responsible for inducing the symptoms in those individuals who are mite or cat allergic. Once this information is determined, the proteins are being isolated in the laboratory and used in the development of improved immunotherapy for allergy sufferers.

One of our other main research interests is to examine the immune responses to bacteria and viruses in young children who are pre-disposed to developing allergy. These studies are particularly important in light of previous research showing that impaired or altered immune responses to pathogens can influence allergy outcomes in children. Our team has looked at the levels of antibodies in blood samples from children to a number of bacteria that cause common childhood infections including *Haemophilus influenzae* and *Pneumococcus pneumoniae*. Our results have shown that those children who are more likely to develop allergy and asthma have lower levels of bacteria-specific antibodies than those children whose risk is minimal. We are also in the process of measuring rhinovirus specific antibody levels in children, as this virus is one of the main causes of the common cold and may play a role in allergy development.

Children's Environmental Health

The Institute's Division of Clinical Sciences was designated as a World Health Organization Collaborating Centre for 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. The Centre also aims to build research capacity by fostering collaborations between developed and developing nations and to date we have been working with researchers in Argentina, Brazil, China, India, Mexico, Nepal and Thailand.

During 2008, we began preparations for 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 will be looking at the lung function of children who have been invited to participate through the local primary schools. Participation involves taking measurements of lung function in children whilst simultaneously monitoring the air quality in this area. By measuring the lung health of children, the air quality and other factors related to respiratory health in the area and comparing the results to similar studies around Australia, variations in lung function, air quality and other risk factors related to respiratory health can be identified. The study has been 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.

Childhood Asthma Study

The Childhood Asthma Study has been following a group of 263 children at high genetic risk of atopy. They were recruited to the study 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. Our research results have shown significant associations between viral infections (such as rhinovirus and Respiratory Syncitial Virus) in the first year of life and the subsequent development of persistent wheeze at five years of age. We also looked at antibiotic use in the first year of life and found that there were no associations between antibiotic use and eczema, current wheeze, current asthma, atopic asthma, allergic rhinoconjunctivitis or atopy at five years of age.

The Childhood Asthma Study 10-year follow-up visits commenced in July 2006 and were completed in August 2008. Data on the children's health as well as environmental exposures since the last follow-up visit at five years were collected. The children underwent blood tests, skin prick tests for allergy and lung function tests. Data from this follow up visit will help us to determine early life factors associated with persistent wheezing and asthma. It will also enhance our understanding of innate and adaptive immune system development as well as factors involved in the development and maturation of the immune system. Analysis of the data continues and results are expected in 2009.

RESEARCH PRIORITY AREA: Cancer

Every year in Western Australia alone, around 60 to 70 children are diagnosed with cancer.

While new treatments mean that many of these children will recover from this disease, our research focus is on why some children don't respond to therapy and relapse. We are also investigating the underlying mechanisms in the development of paediatric brain tumours and ways to reduce their devastating impact.

A broader research project is examining genetic, dietary and environmental risk factors in the development of childhood cancers.

Embryonal tumours

The Institute is managing the Australian arm of an international pilot study of embryonal tumours. The study is taking place in 15 countries around the world and is looking at factors around the time of the birth as well as parental exposures that may increase the risk of the development of embryonal tumours. The pilot study is focusing on two types of embryonal tumour, Neuroblastoma and Wilms' Tumour, while the main study would involve all forms of non-central nervous system embryonal tumours.

Australia is the first country to start the pilot, and in 2008 we began recruitment of children aged up to 14 years to the study. Children diagnosed during the year with either neuroblastoma or Wilms' tumour at one of the nine paediatric oncology centres around Australia were recruited along with their parents. Those diagnosed during 2007 at Princess Margaret Hospital in Perth were also retrospectively recruited. Control children and their parents were recruited via the Electoral Roll, Medicare and the Midwives Notification System of WA.

All families are interviewed about their health prior to conception of the child and during the pregnancy and their medication, alcohol, tobacco and drug use during this period. We also ask about their family's medical history, their occupation and whether or not they have been regularly exposed to pesticides. Mothers are also interviewed about the health of their child with a focus on their first 12 months, their vaccination history and any illnesses or allergies. As a trial, some control families provided DNA saliva samples by post to help us determine the quality and quantity of DNA obtained.

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 leukaemia in children have reached around 75 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 or a return of the leukaemia.

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.

Researchers are also now 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.

Children newly diagnosed with ALL in Australia between 2003 and 2006 were identified through all the paediatric oncology centres in Australia and each was matched to two control children selected by age, gender and state of residence and identified using random digit dialing.

Data was collected through self-administered exposure questionnaires for each parent and food frequency questionnaires for the mother (during pregnancy and breastfeeding), the father (in the 12 months prior to the pregnancy), and child (their current diet and their diet as an infant). Follow-up telephone interviews asked about occupational and other exposures. Blood and cheek swab samples were taken from the case child (in remission) and blood samples were taken from their parents. Control families also provided DNA samples through cheek swabs.

Results from this study are expected in 2009.

Brain tumours

Brain tumours are the second most common cancer affecting children. In contrast to children with leukaemia who have an excellent chance of a cure, those diagnosed with the most common form of childhood brain tumour, medulloblastoma, have a substantially greater risk of succumbing to the disease. Of particular concern is the less than 50 per cent survival rate for children with high-risk medulloblastoma. On top of this, children with brain tumours face the possibility of brain damage and disability associated with surgery, radiotherapy and chemotherapy.

There is clearly a pressing need for safer and more effective treatment options and the most direct way to address this 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.

Our researchers have undertaken a comparison of the expression levels of nearly 15,000 genes in a panel of medulloblastoma specimens and normal brain tissues. Careful analysis of the data revealed several genes that appear to be switched on or off inappropriately in medulloblastoma cells. Researchers are now switching these same genes on or off in cultured normal brain stem cells to see whether it is possible to mimic the features of medulloblastoma. If our approach is successful, researchers will derive a better understanding of the very early events in medulloblastoma development and it will enable them to design new drugs or treatment strategies that target the genes or pathways identified. Ultimately, this work will lead to better and more effective treatment options for our young medulloblastoma patients and a more optimistic future for children affected by this life threatening disease.

Our researchers are now three years into 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.

We continue to collect information from both children with brain tumours and controls using instruments such as self-administered exposure questionnaires for each parent and food frequency questionnaires for the mother, father and child. Telephone interviews ask about occupational and other exposures and DNA (blood or saliva) samples are being collected from the child and parents for genetic analysis.

Recruitment of children to the study will continue until 2010.

RESEARCH PRIORITY AREA: Healthy development

Thousands of families are involved with long term studies at the Institute to answer one of the most fundamental questions - what does it really take for a child to grow up strong, healthy and happy?

The data that we have gathered over many years is now helping us to look at important issues ranging from the real impact of the obesity epidemic to the rise in youth depression and whether children outgrow difficulties with language.

Young people who have grown up in the studies are now helping to shape the future of the research with their active involvement in a consumer reference group.

The 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 largest and most successful studies of pregnancy, childhood and adolescence to be carried out anywhere in the world.

The Raine Study is currently conducting the 16/17 year assessment. The teenagers and their parents complete a comprehensive questionnaire and provide blood and DNA samples. The teenagers participate in a physical assessment as well as further on-line questionnaires and cognitive tests.

The main research areas for the 16/17 year follow up include: physical activity, physical fitness and motor competence; cardiovascular health and blood pressure; polycystic ovarian syndrome and menstrual disorders; non-alcoholic fatty liver disease; childhood precursors of adult cardiovascular disease and diabetes; and the development of adolescent spinal pain.

A Raine Study Youth Reference Group, consisting of study participants, provides a valuable and insightful contribution to the management and running of the study. This is particularly important as the participants reach adulthood with complex and busy schedules proving to be an increasing challenge in recruiting the participant families to the follow-up.

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.

During 2008, the study team conducted 223 assessments with study families, and 75 of these assessments also included a medical conducted at the children's hospital. Final assessments were completed with families from four schools who have taken part in the study for the past three years and additional families were recruited from two new schools. Results have shown that increasing weight is associated with an increased risk for psychosocial and physical health problems.

Initial findings from the Growth and Development Study found that maternal body mass index (BMI) was the strongest predictor of child BMI, highlighting the need to target an intervention to this population. So in 2008, the study team piloted an intervention program for overweight mothers with overweight primary school-aged children. The 13-week group cognitive behavioural treatment program focused on mothers better managing their own weight with the aim of having a flow on effect in the family. The pilot showed a positive effect on maternal BMI and mother and child psychological functioning and the program will be expanded to more families in 2009.

LOOKING at Language

Our LOOKING at Language Study is investigating genetic, neuro-developmental and environmental risks for Specific Language Impairment (SLI) in twins and singletons from two to nine years of age. It is the world's largest study on language emergence and the first to look at predictors of late language.

SLI is a disorder where children struggle with language acquisition for no apparent reason. These children do not have a hearing or intellectual problem, they have a specific problem with language. SLI affects approximately seven per cent of single-born children with otherwise normal development. The rate of SLI in twins is not known.

In 2008, we released results from the study which showed that one in five late-talking toddlers continue to have language problems by age seven. Previous results from the study showed that 13 per cent of two-year-olds are late talkers and that boys are three times as likely to have a delay at that age. However, the new data shows that by seven years of age, 80 per cent of late talkers have caught up and that boys are at no greater risk than girls. While a late start with language doesn't necessarily predict on-going language problems, in our study most school-aged children with impaired language were late talkers. For late talkers, professional evaluation by a speech pathologist and a hearing check are essential as early intervention can greatly assist with a child's language development.

The next challenge for researchers is finding ways to identify which children were likely to outgrow the problem so that interventions could be targeted at those in need.

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 that has already, or is planned to be, linked as part of the project include data on hospital and emergency admissions, child protection, education assessment, intellectual disability, birth defects, cerebral palsy, and juvenile justice.

Currently, the de-identified linked data are being used by researchers to identify multi-level and early determinants of developmental outcomes, and the interrelationships among them. It is anticipated that the research findings will influence future government agency policies, practice and planning initiatives so that they are more preventative, culturally-appropriate and cost efficient.

In 2008, several papers were published including one outlining a new approach to prevent child abuse and neglect from occurring in the first place. In the past decade, rates of child abuse notifications and children being taken into care have doubled. The paper suggested a public health model that includes universal prevention programs such as parenting support and education, targeted prevention strategies for higher risk families and a range of enforced interventions in addition to current strategies that focus on criminal sanctions and removal of children.

The 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 and researchers will work closely with GPs and other medical professionals, as well as social service providers and families to look at the range of services in the region and the types of families who use them. The project could be extended to cover other aspects of family life, such as transitional parenting forced by the fly-in, fly-out nature of mining and military jobs and the pressures faced by working grandparents who look after young children.

In 2008, recruitment for the study began, with mothers enrolled from 18 weeks of pregnancy.

RESEARCH PRIORITY AREA: Infectious disease

Vaccinations may now seem routine, but infectious diseases are still the most common cause of death in children. Our research teams are evaluating new vaccines for a range of common diseases.

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

Through the Institute's Meningitis Centre we are also working to raise awareness of symptoms, support survivors and advocate for ongoing research.

Influenza

Influenza or the 'flu is caused by a highly contagious virus spread by coughing and sneezing. Symptoms include chills, sweating, headache, cough and general muscle and joint pains and in rare cases it can lead to serious complications such as pneumonia or inflammation of the brain or heart.

In 2008, 319 WA volunteers aged 18 to 65 years took part in an influenza vaccine study that involved 7,546 participants from sites around Australia and New Zealand. The study was looking at the effectiveness of the influenza vaccine in this age group. Participants were given either a 'flu vaccine or placebo and were then required to attend the centre for assessment, collection of samples and treatment if needed when they developed an 'influenza-like-illness.' The study is being repeated in 2009 with 100 adults.

Also in 2008, we conducted the Children's Western Australian Influenza Vaccine Effectiveness (WAIVE) study looking at the effectiveness of influenza vaccine in young children and assessing the burden of influenza on families and health services. Children who had presented either to their GP or PMH Emergency Department with suspected 'flu or were hospitalised with influenza, had a nasal swab taken to test for influenza. Parents also completed two questionnaires.

The preliminary results indicate that influenza vaccine protects against more severe influenza illness and greatly reduces the risk of hospitalisation. Based on the 2008 study, a new WAIVE study has been developed and will run from 2009 to 2012 which may provide the information needed to inform influenza vaccine policy for young children in Australia.

Pneumococcal disease

Throughout the world an estimated one million children die annually from pneumococcal disease, most in early infancy.

In Papua New Guinea, pneumonia is the main cause of death in children. Here, there is no pneumococcal vaccination program which puts babies at a high risk of being exposed to the bacteria at a young age. This exposure can result in the development of invasive pneumococcal disease which includes potentially fatal pneumonia or meningitis.

We have been working with the Papua New Guinea Institute of Medical Research on a study looking at whether giving the pneumococcal vaccine at birth is safe and results in a good immune response. The study is taking place in the highlands of Papua New Guinea with enrolled babies randomised to receive vaccinations at different times during their first months of life - at birth-one-two months of age, at one-two-three months of age or routine immunisations which act as a control group.

During 2008, we followed-up all 318 babies to 15 months of age to look for vaccine-induced immune responses, risk of pneumococcal carriage and disease and vaccine side effects. Preliminary findings from the measurement of pneumococcal antibodies indicate that neonatal and early infant immunisation is safe and immunogenic and that it may delay onset of a first episode of pneumonia in young children. The main side effect of vaccination was tenderness at the vaccination site.

Whooping cough

Severe whooping cough (pertussis) is most common in newborn babies, who are too young to receive pertussis vaccination which isn't given until two months of age. We are looking at ways to provide earlier protection against whooping cough infection by vaccinating babies at birth, with the aim of inducing a protective immune response in the first crucial months of life.

In a collaborative pilot study with the National Centre for Immunisation Research and Surveillance in Sydney, we examined the cellular immune responses achieved in a group of children following the standard vaccine schedule (vaccine given at two, four and six months of age) either alone, or together with an additional vaccine dose given at birth and at one month. A blood sample was collected at two, four, six and eight months of age.

The pilot study provides evidence that giving pertussis vaccination to newborn babies induces significantly higher levels of protective antibody as early as two months of age compared to those vaccinated according to the current schedule. At eight months of age, the levels of protective antibodies were similar in all three groups.

From the blood samples, we observed that the memory white blood cells of those babies given the vaccine at birth responded well to the pertussis vaccine protein at eight months of age. We are currently in the process of determining if the immune system of these children is still responsive to the vaccine by the time they reach their second birthday.

Meningitis

Meningitis is a medical condition caused by inflammation of the protective membranes covering the brain and spinal cord, known collectively as the meninges, and is usually caused by bacterial or viral infection. The disease is most common in young children aged up to four years (around 45 per cent of cases) and older teenagers and young adults aged 15 to 24 years (around 28 per cent of cases).

Our Meningitis Centre is committed to making all parents aware of the symptoms of the disease and the need to immunise their children, in the hope that the present impact of meningitis on the nation can be dramatically reduced. For more information about the Centre visit www.meningitis.com.au.

Our researchers are involved in a range of studies into the prevention of meningitis and meningococcal disease. We are now into the third year of a five-year study looking at a combined meningitis vaccine for toddlers. Results so far have been promising showing protective antibodies in toddlers to both *Haemophilus Influenza* type B and Meningococcal C.

The development of an effective vaccine against Meningococcal B is getting closer and our studies in this area continue. Meningococcal B is the last major cause of meningitis for which a vaccine isn't yet available. A study of a new vaccine for adults aged 18 to 40 years began at the end of 2008 with an overwhelming response from participants keen to take part in this important and exciting study. Recruitment for the adolescent phase of the study commenced in early 2009.

Otitis media

Otitis media is an infection of the middle ear with inflammation of the middle ear cavity. It can seriously affect childhood development, school performance and subsequent social and economic wellbeing. 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 research in the regional WA town of Kalgoorlie has collected social, demographic, environmental and biological data to investigate the causes of otitis media in Aboriginal and non-Aboriginal children. Results released in 2008 show a strong link between childhood ear infections and exposure to tobacco smoke. Otitis media was diagnosed at least once in 55 per cent of Aboriginal children and 26 per cent of non-Aboriginal children. Sixty four per cent of Aboriginal children and 40 per cent of non-Aboriginal children were exposed to environmental tobacco smoke. If we eliminated exposure to tobacco smoke we estimate that we could reduce ear infections by 27 per cent in Aboriginal children and 16 per cent in non-Aboriginal children.

Our new Family Study of Ear Infections in WA Children is collecting salivary DNA from 1000 children with recurrent acute otitis media to try to identify the genes that contribute to the disease. We know that some environmental factors increase ear infections while others help protect against them. We also know that some families are more likely to have children with ear infections than others so genetics plays a part. Our task is to find out which genes are responsible for ear infections, and how this relates to all of the environmental factors.

RESEARCH PRIORITY AREA: Social and emotional wellbeing

One in five young people in Australia struggle with a mental health problem and the incidence is rising.

Our research looks at the factors that are causing this increase and what can be done to help make a child more resilient.

Some of the solutions start before birth by supporting the mother to have a less stressful, healthier pregnancy. Others look at the role of nutrition and parenting.

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.

In 2007, we developed and launched the ARBOR (Active Response Bereavement OutReach) Service for people bereaved by suicide. 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. Referrals are made directly with ARBOR or through the Coronial Counselling Service in WA.

The ARBOR service came about after we conducted a needs assessment with people bereaved by suicide. We then developed an information and support pack to assist those bereaved by suicide or other sudden death and ARBOR followed, inspired by an outreach service in the USA.

Evaluation of the service is being undertaken by Edith Cowan University with a comprehensive plan of evaluating the interagency collaborations that assisted in the development and delivery of the service, qualitative and quantitative data collection on wellbeing outcomes of clients and evaluation of the impact of being involved in the service for the peer supporter volunteers.

Maternal stress during pregnancy

Using data collected from more than 1700 children in the WA Pregnancy Cohort (Raine) Study, researchers have found that children whose mothers were stressed during pregnancy are at higher risk of developing behavioural and emotional problems.

The findings were drawn from child behaviour checklists undertaken at two and five years of age. The analysis found that maternal smoking, low income during pregnancy, multiple 'baby blues' symptoms after birth and stress were each associated with poorer behavioural and emotional outcomes in preschool children. The risk was also higher in children of non-Caucasian mothers and those who breastfed for shorter durations.

The research highlights the importance of early intervention, family support and parental education, particularly for mothers who have lower levels of education, who are socially isolated or otherwise disadvantaged.

The results are some of the first of their kind in Australia to enable quantification of the potential benefits which could be achieved through effective public health strategies and community education. To reduce the rising rates of behavioural and emotional problems in children, a good place to start is in pregnancy.

However, researchers noted that women who had experienced some of these risk factors during pregnancy should not feel more anxious about these findings. While factors such as stress might put children at higher risk, it doesn't mean that they will develop problems and there are many opportunities throughout a child's early years to promote healthy development.

Stress and brain development

During adolescence, the brain undergoes a period of synaptic pruning or elimination where the brain reduces circuits and connections created over time that aren't being used, in favour of those that are the most efficient. As pruning takes place, the brain is 'rearranged' and the functional circuits that are most efficient for cognitive development are preserved. However, if the adolescent brain fails to prune appropriately, the result could be unacceptable psychosocial behaviour or even mental health problems like depression or schizophrenia.

It is possible that the stress hormone cortisol may influence the process of pruning as the brain has many cortisol receptors and over-exposure to the hormone may impact on which brain connections are eliminated during adolescence.

It's an area of science in which there is still much to learn and the Institute's neuroscience group is exploring teenage brain maturation to gain a better understanding of how cortisol levels relate to the development of mental health and physical diseases.

The team is examining stress in teenagers involved in the WA Pregnancy Cohort (Raine) Study. Thinking skills are tested using specially-designed computer games. Cortisol levels in saliva and blood are monitored when the teens are relaxed (to provide a base line) and then following a challenging new situation which triggers the release of cortisol. As well as assessing how well the teenagers cope with stress, information on mental health and cognitive and neuroendocrine development is collected through questionnaires.

Breakfast and mental health

Research results from the Institute have shown that a high quality breakfast, with foods from at least three different healthy food groups, is linked with better mental health in 14-year-old boys and girls.

Researchers asked over 800 teenagers in the WA Pregnancy Cohort (Raine) Study what they ate for breakfast and scored this based on their intake of the core food groups. Mental health was assessed using a child behaviour checklist.

They found that just one in four teens ate a high quality breakfast, and the two most common core food groups eaten at breakfast were breads/cereals and dairy products. Disturbingly, a small proportion of teens did not eat any items from the healthy core food groups for breakfast over the three day study period.

Increasing the variety of nutrient intake at breakfast is as simple as adding a sliced banana to toast, sprinkling dried or canned fruit over cereal or including a glass of milk with your breakfast meal.

For every extra food group eaten at breakfast, the associated mental health score improved and this may be because mental functioning is affected by the absorption of a variety of nutrients, including calcium, iron and B group vitamins

Research has already shown that students who eat breakfast pay more attention in class, retain more information and are more interested in learning, but this is the first study to show that variety at breakfast is also important.

Suicide prevention

Self-inflicted injury (suicide and other undetermined intent) is the leading cause of injury death in Western Australia, ahead of motor vehicle and other transport injury deaths. Around 250 West Australians end their life by suicide each year.

The Institute maintains the WA Coroner's database, a continuous 21 year collection of data from every completed suicide in WA which provides one on the richest sources of suicide data in Australia. Information from the Coroner's database helps to improve our understanding of suicide and suicide prevention, aids in the development of training materials and resources and informs future suicide prevention strategies.

The Institute's Gatekeeper Training Program targets professionals in positions most likely to engage with those at risk of suicide. This approach maximises return on investment by equipping those most likely to use their knowledge and skills. Targeting key professionals also ensures that the resulting interventions are at an appropriate level of expertise and that trainees operate within a well developed ethical framework and disciplinary supervision structure. The training is strongly evidence-based, informed by the most accurate information on suicides in WA from the WA Coroner's database and other research evidence.

We are also linking data from the Coroner's database with data from a Deliberate Self Harm Database developed by the Institute and other health and welfare sources of data. We have also developed a range of resources which provide information for parents, carers and families concerning suicidal behaviour.

RESEARCH PRIORITY AREA: The early years

Nurturing a child's development is important at any age, but there is a particular window of opportunity from birth to around five years of age to lay down patterns that will provide life-long benefits.

The early years is a time of massive brain development, rapid growth and learning.

The Institute has been a driving force behind the introduction of the Australian Early Development Index which provides communities with a measure of how their children are developing and what can be done to boost their opportunities in those crucial early years.

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 will help 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 for Child Health Research in Perth.

Following the success of the first phase of national AEDI project from 2005 to 2007, the Australian Government has provided $15.9 million for the national implementation of the AEDI in 2009. This will in effect be the first national census of the developmental outcomes of children at five years of age conducted anywhere in the world.

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 evaluating how the AEDI is working for Indigenous children, taking into account Indigenous perspectives of children's development and culturally-valued ways of learning and is working with communities to develop tools and resources to assist in capacity building in communities with Indigenous populations.

Breastfeeding

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 have been conducting a project to gather information to allow effective planning of a health promotion strategy for breastfeeding in Perth. We have been looking at existing evidence and information about breastfeeding and also talking to first-time mothers to identify and delve into the issues surrounding initiation and continuation of breastfeeding.

Globally, a number of breastfeeding interventions have been trialled, ranging from education of mothers on the benefits of breastfeeding to the development of hospital-based interventions. The literature is supportive of post-natal interventions in improving rates of initiation as well as increasing duration of breastfeeding.

In our focus groups with mothers of six to 11-month-old babies, we asked about factors and issues that influenced their breastfeeding at individual, group and society level. Some of the responses included physical difficulties to breastfeed, a general lack of consistent information, first-time mothers being unprepared for the challenges of breastfeeding and a mother's perception of society's views of breastfeeding.

The project found that the most powerful set of factors determining breastfeeding success were a woman's commitment to breastfeeding, realistic expectations of the challenges associated with breastfeeding, having a supportive partner, being prepared for breastfeeding and making a personal decision to breastfeed.

Best Beginnings follow-up

The Best Beginnings program was launched in Western Australia in late 2000 as part of a comprehensive multi-department response to the health and wellbeing of children during their early years. Best Beginnings targets vulnerable families and offers long-term contact between home visitors and families. Intervention commences just before or soon after birth and includes 19 home visits during the first two years of the baby's life. The program is based on evidence about both the importance of the early years of life in determining a child's life chances and effective home visiting practice.

The Institute has conducted a long-term follow-up of former Best Beginnings clients in Western Australia to assess the impact of the program. The research has shown that the program is effective because it takes into account the client's diverse levels of personal resources, different types and forms of support systems and a variety of relationship types in the design and delivery of services to them. Parents were shown to have a commitment to their children and to doing their best to give them a good start and they were open to new ways of enhancing their parenting skills and knowledge. The Parent Support Workers delivering the program enabled parents to be more effective in their parenting by offering reliably high quality information and advice. Four out of five former clients believed Best Beginnings had a positive impact on how well their child grew and developed.

This research reinforces the need for a flexible, responsive and strengths-based home visiting service like Best Beginnings in WA.

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.

This pilot study, conducted in collaboration with the CSIRO in Adelaide, will tell us whether the food children eat affects the health of their DNA.

We developed Food Frequency Questionnaires and Dietary Records to collect information about specific nutrient intakes such as folate, calcium, magnesium, zinc and vitamins B12 and B6. Each child also gave us a small blood sample which was used to assess the level of nutrients in the blood, and to measure various markers of DNA damage.

Seventy-five children aged 3, 6 or 9 and their mothers took part in the pilot study. They provided information about their child's diet several times over a four month period.

The laboratory analyses of micronutrients and DNA damage and the comparison of the questionnaires and dietary records are currently under way with results expected in mid-2009. The larger study of children's diet and DNA damage will commence later in 2009.

Longitudinal Study of Australian Children

The Longitudinal Study of Australian Children is looking at the development of the current generation of Australian children to improve our understanding of the complex interplay of factors that foster or impede healthy early child development.

The study began in 2004 with the recruitment of 5000 families with babies and 5000 families with four to five year olds. The study is examining a range of factors including physical health, social, cognitive and emotional development as well as information about their temperament and their family, child care, school, neighbourhood and community experiences. The Institute's Professor Steve Zubrick chairs the LSAC Consortium Advisory Group.

During 2008, research findings from the Wave 2.5 data collection were released. The results show that one in three children with high levels of television watching often turned the television on themselves and over nine in 10 children aged seven to eight years had a computer at home. Just over 70 per cent of two to three year old children were reported to be attending child care and the majority of fathers were involved in reading to their child, playing indoor or outdoor games with them and involving them in daily activities. Wave 3 data collection also took place in 2008 with thousands of face-to-face interviews being conducted with parents.

Also in 2008, the *Life at 3* television documentary series aired, which draws upon the methodology and research findings of the LSAC. The documentary is following 11 children and their families with coverage of children's behaviour and milestones and the impact of factors such as parents' relationships, finances, work and health.

RESEARCH PRIORITY AREA: Understanding disability

Often the first question asked by any family of a child with a disability is why did this happen?

At the Institute, it's our focus too. Through genetic analyses and comprehensive databases, we are gathering evidence on a range of rare and more common conditions.

Our concern is also to understand how those conditions impact on the lives of the children and their families. By building the big picture comes ways to prevent disability and to improve outcomes for the children who are living with the challenges that it presents.

Three-year-old Mikayla Kennelly and her family are part of our Rett syndrome study. Photo courtesy The West Australian

Rett syndrome

Rett syndrome is a rare but serious neurological disorder that affects around one in every 10,000 female births in WA. It is caused by a mutation in the *MECP2* gene on the X chromosome and there is no cure.

Our AussieRett database collects comprehensive health, daily living and service provision information about all Australian girls born with Rett syndrome since 1976. Genetic and clinical information is also collected such as electroencephalographs (EEGs), electrocardiograms (ECGs) and bone densitometry. Video footage captured by families provides an extremely important and innovative source of information about movement issues in girls with Rett syndrome. The footage gives researchers a moving picture of the girls' participation in daily living activities and allows us to code gross motor function, hand function and hand stereotypes.

Our international database of Rett syndrome, InterRett, grew by around 20 per cent in 2008 with information submitted via online questionnaires. Families from more than 40 countries are involved with the majority coming from Australia (21 per cent), USA (18 per cent) and France (13 per cent). The translation of the questionnaires into Spanish, French, German, Italian and Mandarin allows non-English speaking families to participate.

Scoliosis is a common orthopaedic complication that, by 13 years of age, has developed in approximately 75 per cent of girls with Rett syndrome. We have developed Clinical Guidelines for the management of scoliosis in Rett syndrome, incorporating clinical and parental perspectives, which will be disseminated both within Australia and internationally.

Alcohol in pregnancy

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

Over the last few years, we have developed and distributed resources to more than 3,500 health professionals to support their knowledge and advice to pregnant women and women of child-bearing age about alcohol use during pregnancy. We are currently analysing evaluation questionnaires and comparing them with data collected before the resources were available. The project has demonstrated the importance of sustaining the resources beyond the term of the project and making them available to health professionals throughout Australia.

We have also looked at the consequences of heavy and binge drinking in pregnancy with a study investigating the relationship between prenatal exposure to alcohol and the effects on fetal growth and preterm birth. A survey of a random sample of 4719 women, who gave birth in WA between 1995 and 1997, collected information such as how often they drank alcohol, the amount of alcohol consumed in each occasion and the types of alcoholic beverage consumed. Results show that pregnant women who drink more than one to two standard drinks per occasion and more than six standard drinks per week increase their risk of having a premature baby, even if they stop drinking before the second trimester. The risk of preterm birth is highest for pregnant women who drink heavily or at binge levels, drinking more than seven standard drinks per week, or more than five drinks on any one occasion.

Hypospadias

Hypospadias is a birth defect in boys that affects the penis. Around one in every 170 boys in Western Australia has the condition and this has been increasing in recent years. Boys with the condition may have problems urinating (this can cause bladder or kidney infections) and fertility problems as adults. Hypospadias can be fixed with surgery.

At around eight weeks in pregnancy, the reproductive system of boys develops and male hormones such as testosterone are released. Scientists have found that some environmental substances (found in many everyday household items such as pesticides, plastics, cosmetics, paints, detergents and food) can block the release of testosterone which may lead to problems in the development of the genitals. We do not know exactly how much of one substance is too much, or which substances combined together start to cause problems by blocking male hormones. Genes may also play an important role as some families may have more than one male relative with hypospadias and some people may be more affected by specific environmental substances than others.

New research at the Institute is aimed at increasing our understanding of why some boys are born with hypospadias. The study will use genetics to determine whether any genes are involved in the development of hypospadias. We will look at patterns, or variations, in specific genes to see which genes are important. We may also look at the chemical modifications that control how these genes function in our bodies to determine how specific environmental substances may influence our genes and their functions. Recruitment of both boys with and without the condition will commence in 2009.

Autism Spectrum Disorders

Autism Spectrum Disorders (ASD) is an umbrella description which includes autism, Asperger syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder Not Otherwise Specified. They are characterised clinically by significant impairment in social interaction and communication, and many children have difficulties integrating into society with each requiring varying degrees of supervision and support in daily living.

The WA Autism Register serves as a primary resource to researchers, clinicians and service providers to provide knowledge of the diagnostic patterns of these complex disorders. The Register has collected information since 1999 on newly diagnosed cases in WA and to date the Register has collected information for more than 2200 children, adolescents and some adults.

We are also part of a world-first, international collaboration with Denmark and the USA looking at trends in diagnoses and incidence of ASDs. The observed and widely-reported significant increase in ASDs has major implications for health service providers, educational institutions and families. However, there is currently no strong data available on the increase in ASDs with increased awareness of parents and clinicians, changing diagnostic criteria, methods of reporting and case ascertainment possibly accounting for this apparent increase. The three collaborating Registers have the capacity to provide the best possible estimate of reliable trends of ASDs and the results could provide valuable information for the future planning requirements of intervention services for children with an ASD.

Intellectual disability

People with an intellectual disability have difficulties with thought processes, learning, communicating, remembering information and using it appropriately, making judgements and problem solving. An intellectual disability may become apparent early in life or in the case of people with a mild intellectual disability, not be diagnosed until school age or later. Many people with an intellectual disability also have physical disabilities.

The Institute's Intellectual Disability Exploring Answers (IDEA) database enables research into the causes and prevention of intellectual disability. Information in the database is based on data from the Disability Services Commission since 1953, as well as information from the Department of Education for births since 1983. These records are linked to each other and de-identified for use by researchers.

In 2008, information from the database was used in a range of studies including one measuring the burden of genetic disease in the WA population, another looking at a population health approach to child abuse and neglect and a study investigating accommodation support for West Australians with intellectual disability.

A new study is exploring the challenges faced and outcomes achieved by students with an intellectual disability as they move from secondary school into adult life. The five-year study which will commence in 2009 will investigate the individual, family and societal factors which positively and adversely affect outcomes for young people with an intellectual disability (as they move into adulthood) and their family, as measured through participation, wellbeing and quality of life.

Senior staff

Jenefer Blackwell
BSc(Hons) PhD FMedSci
Genetics and Health

Originally from Perth, Professor Blackwell has held positions at the London School of Hygiene and Tropical Medicine and Cambridge University. In 1998, the Cambridge Institute for Medical Research was established with Professor Blackwell as Founding Director. In 2007, she joined the Telethon Institute and established the Division of Genetics and Health. Professor Blackwell has a long-standing interest in identifying the genes that determine susceptibility to various diseases including leishmania and tuberculosis infection, otitis media and the birth defect hypospadias. Professor Blackwell holds a Professorship at The University of Western Australia and is an Honorary Senior Scientist at the Cambridge Institute for Medical Research.

Carol Bower
MBBS MSc PhD FAFPHM DLSHTM
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 the establishment of the WA Birth Defects Registry. In the 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

Professor Garlepp joined the Institute in 2008 from Curtin University of Technology 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.

Robert Ginbey
BA BEd Grad Dip Public Sector Mgt MACE
Administration & Corporate Services

Mr Ginbey obtained his initial tertiary qualifications at The University of Western Australia and commenced his teaching career in the State's southwest followed by several positions in Papua New Guinea, accepting a tenure at Port Moresby SHS in Papua New Guinea. Mr Ginbey has held several positions within both State and Federal government agencies including the WA Premier's Office and the Department of Community Development. In 1995, Mr Ginbey joined the Institute as Head of Administration and Corporate Services, where he has been instrumental in building the division as well as coordinating the funding, planning and construction of the Institute's current building, which was completed in 2000.

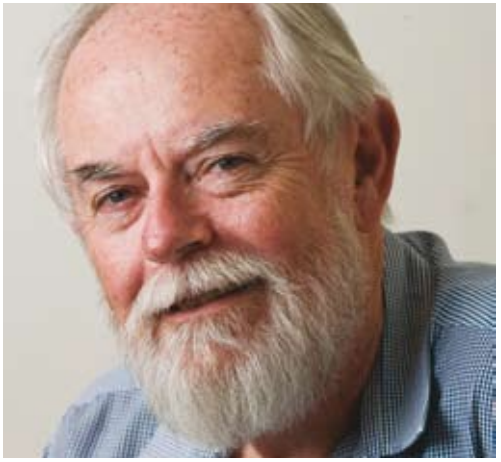
Prue Hart
BSc(Hons) MSc PhD
Inflammation Laboratory

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 is a NHMRC Principal Research Fellow and an Adjunct Professor at UWA.

Colleen Hayward
BEd BSc
Kulunga Research Network

Professor Hayward is a senior Noongar woman who has an extensive background in a range of areas including health, education, training, employment and housing as well as significant experience in policy and management. Professor Hayward was the deputy Chief Executive Officer of the Aboriginal Legal Service of WA prior to commencing as the Manager of the Institute's Kulunga Research Network. In 2008, she was named National NAIDOC Aboriginal Person of the Year for her long-standing work for, and on behalf of, Aboriginal and Torres Strait Islander communities. At the end of 2008, Professor Hayward accepted the position of Head of Kurongkurl Katitjin, the Centre for Indigenous Australian Education and Research, based at Edith Cowan University.

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.

Senior staff

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.

Bruce McHarrie
BCom CA
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 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.

Sven Silburn
BSc(Hons) MSc(Clin Psych) MAPS
Centre for Developmental Health

Professor Silburn trained in clinical psychology in South Africa and then practiced in clinical child psychology with the WA Health Department from 1978 to 1990. He joined the Institute in 1991 and has helped develop a program of applied research in child and adolescent mental health, school and community approaches to suicide prevention and Aboriginal child health. Professor Silburn provides advice to the Longitudinal Study of Australian Children (LSAC) and serves on the Steering Committee for the Longitudinal Study of Indigenous Children (LSIC). At the end of 2008, he took up a position at the Menzies School of Health Research, but maintains close collaborative links with the Institute and Curtin, where he holds an adjunct Professorship.

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.

Paul Watt
BSc (Hons) D.Phil
Drug Discovery Technology Unit

An Adjunct Associate 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, where he is Executive Director and Vice President of Corporate Development. Professor Watt has led his research team, in collaboration with the Fox Chase Cancer Centre in the USA, in the development of Phylomer® peptides, molecules designed to target proteins and block their interactions.

Stephen Zubrick
MSc AM PhD
Population Sciences

A Professor at Curtin, 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 of Technology. 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.

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 area of children's cancer and leukaemia, infectious diseases and diabetes.

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.

Phylogica

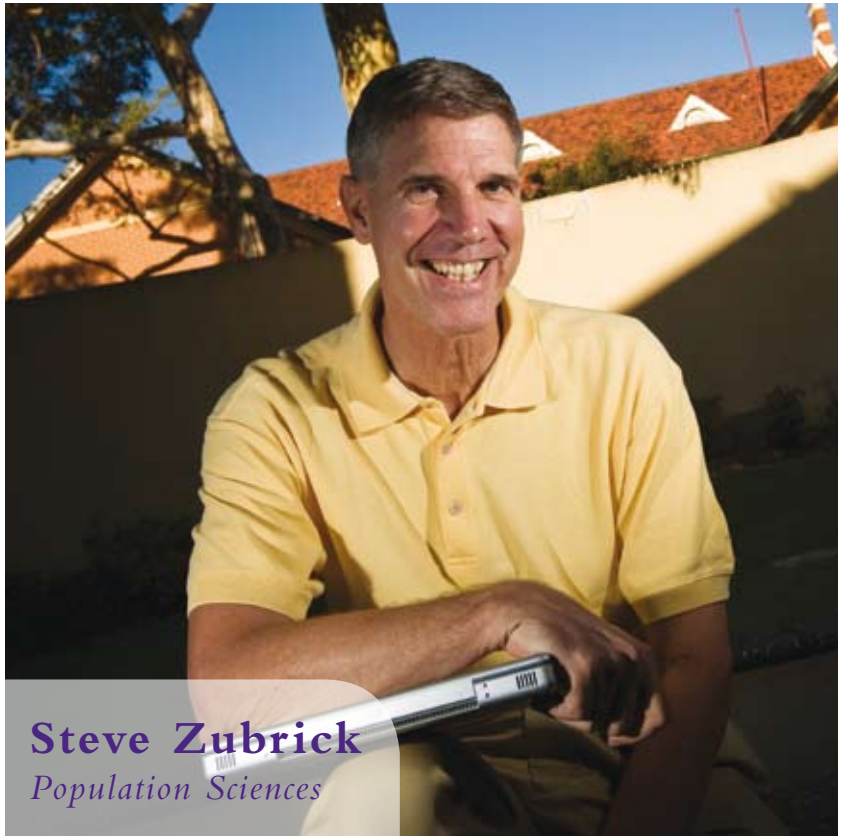
Drug discovery company Phylogica (ASX:PYC) is the first commercial spin-out from the Telethon Institute for Child Health Research. Phylogica's innovative Phylomer® technology targets and blocks disease protein interactions, constituting a drug discovery engine designed to produce cost-effective therapies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



Steve Zubrick

Population Sciences

Professor Steve Zubrick has a passion for growing up children into healthy adults and for the last three decades, he has made it his life's work to find out the best ways to do this.

"I want to develop a more comprehensive picture of the pathways that lead from conception to adulthood and that focus upon the ability, at each stage of the life course, for the developing person to be able to optimally participate – socially, economically, and civically," explains Steve.

Steve completed his doctoral and postdoctoral work in psychology at the University of Michigan. Before joining the Institute in a part-time capacity in 1991, Steve worked in Western Australian hospital and outpatient mental health settings for many years.

"My clinical work in the mental health field in WA really opened my eyes to the challenges that some members of our society face during childhood that can have lasting influences as adults," says Steve.

Steve became a full-time Institute staff member in 1997 and he currently heads the Division of Population Sciences, overseeing the research teams that study the social, economic and psychological determinants of human development. He cites his involvement in the initial creation and findings from the Western Australian Child Health Survey, closely followed by the creation and findings from the Western Australian Aboriginal Child Health Survey, as two of his career highlights.

"The amount of hard work that went into these two studies and the commitment of the staff and families involved was enormous, but the success of both of the studies and the fact that they are today being used to drive policy and planning of health services around the state, and indeed the country, make it an extremely satisfying and worthwhile experience."

Along with his role at the Institute, Steve also holds a position in Curtin's Centre for Developmental Health. However, in each role he holds, Steve sees one of his most important tasks as developing the skills and knowledge of his researchers.

"I'm certainly passionate about building good teams and I believe that teaching the next generation of research leaders is the key to continuing the great work that we have started here, and hopefully making significant changes to the lives of people," says Steve.

Steve has a reputation as one of Australia's leading authorities in the epidemiology of child and adolescent mental health and as such, his knowledge and skills in this area are highly sought after. In 2002, he was asked to chair the Consortium Advisory Group that provides advice to the Longitudinal Study of Australian Children (LSAC). This study is following 10,000 Australian children over a seven-year period, looking at a range of outcomes including behavioural and emotional adjustment, language and cognitive development, readiness to learn, overall health, physical development and social competence.

"The LSAC adopts a holistic approach to child development, being concerned with outcomes across multiple domains of development, which parallels the work we are doing here at the Institute," explains Steve.

Through Steve's knowledge of LSAC, he has appeared in the '*Life*' documentaries which aired on ABC TV. The series follows a dozen children from birth and explains stages in their growth and development using the sociological and scientific data collected from the LSAC study children.

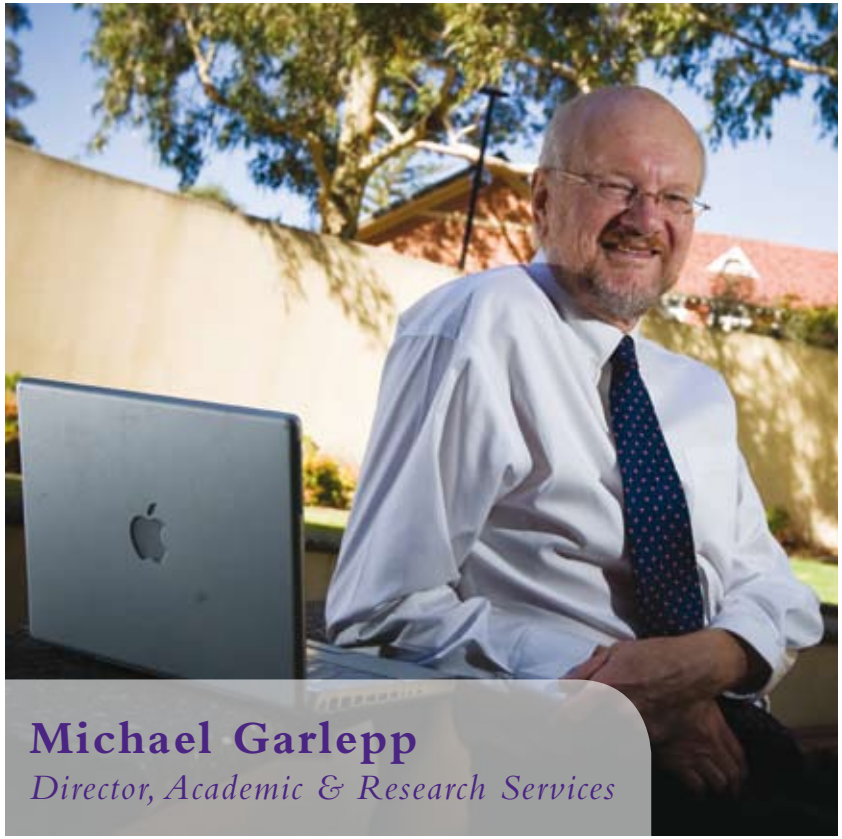
"I really enjoyed participating in the Life program as it was great to see our research being beamed straight into the loungerooms of the families that will hopefully benefit from it most," he says.

Although Steve has contributed significantly to the knowledge base of the healthy development of Australian kids, he believes there is still much more he has to achieve.

"I'd like to establish better forecasting and modelling of human development outcomes at a population level in Australia. We need a better capacity to predict consequences of decisions in health, education and employment and training and communicate these consequences in a more relevant way," he says.

"My ultimate goal is to see the translation of our psychological and social research findings into relevant and timely policies and actions on the part of governments and private agencies - to use these studies in a way to positively influence the lives of children and young people in Australia and abroad," says Steve.

When not wearing his research hat, Steve can be found sailing his boat on the gentle waters of the Swan River with his family and good friends. His other passions in life include walking, reading and listening to music.



Michael Garlepp

Director, Academic & Research Services

Mike is one of the newest faces around the Institute but at nearly six foot four inches, he is hard to miss! Mike joined the Institute in August of 2008 as Director of Academic and Research Services, armed with extensive experience and knowledge gained from a long and illustrious career in research and academia.

Mike originally trained as a pharmacist at what was then the WA Institute for Technology (WAIT, now known as Curtin). After a two-year stint in the Australian Army in charge of pharmacy at 4 Camp Hospital in Townsville, he worked in retail as a pharmacist for a year before commencing a Bachelor of Science at UWA.

"Whilst I enjoyed my time as a pharmacist, I found the research aspects of medical science particularly interesting, and so I decided to enrol in a Bachelor of Science degree with majors in microbiology and pathology," explains Mike.

Mike graduated with First Class Honours and for the next ten years, he worked part-time as a retail pharmacist whilst lecturing part-time to pharmacy students at WAIT and science and medical students at UWA. In between all of that, he somehow managed to complete his PhD thesis in Immunology at UWA!

"Yes, those were busy times, there's no doubt about that," admits Mike. "But I was really enjoying the combination of the research and the teaching, and when you're enjoying yourself, it doesn't seem like hard work!"

Mike's PhD thesis concentrated on the autoimmune disease Myasthenia Gravis, a neuromuscular disease that affects the muscles where antibodies block the receptor for the neurotransmitters leaving the muscle weak and fatigued. This project ignited Mike's interest in autoimmunity which, along with research into the malignant cancer mesothelioma, became his major research focus for the next three decades. It was work that took him overseas for postings at the London Hospital Medical College and the University of Calgary in Canada.

Mike says being involved in the definition of genetic factors involved in autoimmune muscle disease and in the early stages of gene modification of tumour cells are some of his research career highlights.

"Throughout all of my research, I was driven by a desire to determine what causes disease and at the same time working out better methods of treatment so that one day, real people might benefit from my work," says Mike.

During his research career, Mike maintained his lecturing duties before holding senior academic positions at Curtin, including the Acting Executive Dean of Health Sciences, the Acting Pro-Vice Chancellor of R&D and Head of the School of Pharmacy. As part of his university associations, Mike has supervised over 20 Higher Degree by Research students and 12 Honours students. So when the position of Director of Academic and Research Services at the Institute was advertised, it seemed like the perfect fit.

"After many years of research and work in academia it seemed appropriate that I use my experience to enhance the research and the careers of medical researchers," explains Mike.

"In that regard, I felt that the mission and aims of the Institute were worthy of supporting for the remainder of my career."

In his role at the Institute, Mike is responsible for overseeing the research and academic services programs. Having been both a student and also a supervisor to many more (he is currently co-supervising two Institute PhD candidates), Mike has a particular interest in the Institute student group and ensuring that students have the best experience possible.

"I think we have a great support network for the nearly 90 or so students completing their projects at the Institute, and I am really keen to establish a strong mentoring program to boost this support," says Mike.

"I have found in my experience that good mentoring is particularly important for young researchers in order to maintain a focus on the difficult questions in the face of the occasional setback."

Mike has thrown himself into Institute life which has already included a performance as Agnetha from ABBA (complete with long blonde wig and spandex!) in a skit at the 2008 staff Christmas celebration.

"I was told that based on tradition, part of my role would likely involve dressing up in women's clothing and making a fool of myself in front of my colleagues - I didn't have to wait long to find out they weren't kidding!" laughs Mike.

When Mike is not taking part in Institute activities, he can be found playing nine holes of golf or a game of basketball and with two sons over 6 feet in height as well, it is no surprise that Mike is President of his beloved basketball club, the Perry Lakes Hawks. At other times, he can be found enjoying good food and a nice glass of wine in the company of his family and friends.

Consumer and community participation

Consumer and community participation is doing research with consumers rather than research on, about or for consumers. It is an active partnership between consumers and researchers.

The Institute, in collaboration with UWA's School of Population Health, is leading consumer and community participation activities within Australia.

The Institute's Consumer and Community Advisory Council, which was established in 2006, continues to provide advice and input on a range of issues and topics.

During 2008, the Council successfully nominated Institute staff members Jan Payne and Heather D'Antoine, from the Alcohol in Pregnancy Project, for Excellence Awards from the Health Consumers Council of WA.

Discussions were held between the Council and senior research staff regarding potential consumer and community participation activities for a major National Health and Medical Research Council grant application, which the Institute subsequently won.

The Council also assisted in the establishment of a community reference group for the Kwinana children's respiratory health study as well as providing ongoing support to the Infectious Diseases Community Reference Group, the Alcohol and Pregnancy Project community reference groups and the Raine Study 'T' Team.

Consumer and community members associated with the Institute's research projects were able to take part in a training workshop to learn more about how research works.

Consumer and community participation activities will expand in 2009 to include a series of 'community conversation' seminars based on the Institute's research themes and a program to acknowledge good practice in consumer and community participation at the Institute.

At the end of 2008, Ben Horgan completed his term as the inaugural Chair of the Council, a position which will be taken on by Julie Ireland in 2009.

Involving People in Research Symposium

Hosted by the UWA School of Population Health and the Institute, this national symposium was held in Perth in March 2008.

The symposium attracted speakers from around Australia and the world and provided a learning and sociable environment for people with an interest in supporting and promoting consumer involvement in health research.

The symposium was a forum for people to explore important issues and stimulated discussion about the development of future plans and directions for consumer and community participation in health and medical research.

Leading researchers and consumer and community advocates shared their stories, experiences and insights on developing collaborations and partnerships to increase consumer and community participation.

A communiqué was developed calling for the National Health & Medical Research Council to develop ways to further support consumer and community involvement in research.

More than 240 people attended the symposium including 38 consumers, 32 community and non government organisation members, 25 students, and 155 researchers, health professionals, research administrators and health department staff.

Images from the Involving People in Research symposium.

Corporate and community partnerships

Fundraising focus

The Institute finds itself at a time in its evolution when consolidating our financial future is of paramount importance. An overarching goal is to build the finances in the Institute's Children's Future Fund to ensure that the Institute has an income stream that will not only support our team of world class researchers, but allow us, as an Institute, to pursue a strategic agenda. That includes having the resources to react to emerging issues in child health and wellbeing, capitalizing on new technologies and actively recruiting exciting research groups that complement our work program.

The Institute has a multi million dollar fundraising goal where fresh initiatives are the key to reaching out to current and prospective supporters. The Institute is fortunate that its work and advocacy attracts national and international attention, giving supporters confidence that the Institute is strongly delivering on its mission to undertake high quality research and to see the results translated into real action to improve the health and wellbeing of children here and around the world.

Our team is in touch regularly with our many corporate and private supporters, Australian and International philanthropists, philanthropic Foundations and Trusts and our Alumni, to keep them informed of our major achievements, promoting the Institute as one of the world's best child health and wellbeing research organisations.

Fundraising and Corporate Partners

Our success to date would not have been possible had corporate and personal supporters not maintained their faith and interest in the groundbreaking work of the Institute.

We acknowledge the vital support we continue to receive from the people of Western Australia through our founding sponsor, Channel 7's Telethon. As one of Telethon's major beneficiaries, their support has formed a cornerstone of the Institute's success, with that income central to supporting new research, emerging researchers and the provision and maintenance of equipment and facilities.

New Horizons

The documentary '*Risking Our Kids*' presented a wonderful opportunity to highlight the groundbreaking nature of the Institute's work and to reach out to a new audience. The team coordinated a targeted campaign to potential new supporters to follow up on the awareness generated by the film.

The Institute was also invited to participate in the G'day USA program in New York. The event facilitates relationship building in the United States. It generated a number of functions that allowed us to raise awareness of Australian research and to develop new contacts with a view to establishing an international network of supporters and promoters.

"What could be more important than the health and wellbeing of our future leaders, workers and parents? The needs of children and their families should be the top priority of governments and businesses. A society that values children values its future."

Professor Fiona Stanley

Anita van den Biggelaar

Infectious disease researcher

Hailing from the Netherlands, Anita knew during her undergraduate studies in biomedical science that she wanted to work in developing countries and help the people who need it most.

"I was always interested in immunology and infectious diseases, so a logical option was to study how the immune systems of different populations can make them more or less susceptible to certain diseases – I like to think of myself as an 'immuno-epidemiologist'," says Anita.

Anita completed her Masters and PhD projects at the Department of Parasitology at Leiden University in the Netherlands, where she studied the parasitic diseases *filariasis* and *schistosomiasis*.

"Parasitic disease is especially prevalent in developing countries where there are often conditions of overcrowding, poor sanitation and little in the way of health care," says Anita.

"As part of my Masters, I travelled to Sulawesi in Indonesia and spent a year in the field. Then, for three years of my PhD project, I would spend three months in Leiden in the lab and then the next three months in Gabon in central Africa running the field studies," explains Anita.

"Spending time in those developing countries was invaluable as not only is it important as a student to be in the field and collect samples yourself, it also let me see first-hand the people that I hoped my research would benefit."

In between her studies, Anita worked as a freelance science journalist and following completion of her PhD, became a senior epidemiologist for a regional health authority in the Netherlands. But following another research position looking at infectious disease in the elderly in Ghana, Anita's passion for research in developing countries was re-ignited.

"During my time in Ghana, I realised that despite the interesting topic I worked on, I definitely wanted to focus on young children, as improving the health of children probably has the biggest impact, also for disease risks in later life," Anita says.

"The invitation from Pat Holt to join his team, as an 'adventure-based immunologist', working on the pneumococcal immunisation trial in Papua New Guinea highlands offered me the opportunity to make this shift."

So in late 2004, Anita and her family (husband Maurice and daughter Zuza) packed up their home and headed down under where Anita became an investigator on the PNG vaccine trial project.

"*Streptococcus pneumoniae* causes a large number of babies to become very sick in PNG, and in some cases it can lead to their death," explains Anita.

"We are looking at the safety and immunological feasibility of giving them a vaccine when they are first born rather than when they are a few weeks old (as occurs in Australia) and most of them already carry the bug. At the same time, we are trying to see how the immune systems of these babies differ from those of babies born here in Perth."

Anita admits that the logistics of conducting a study like this in a developing country with limited resources can be quite challenging, but says she has a great team around her.

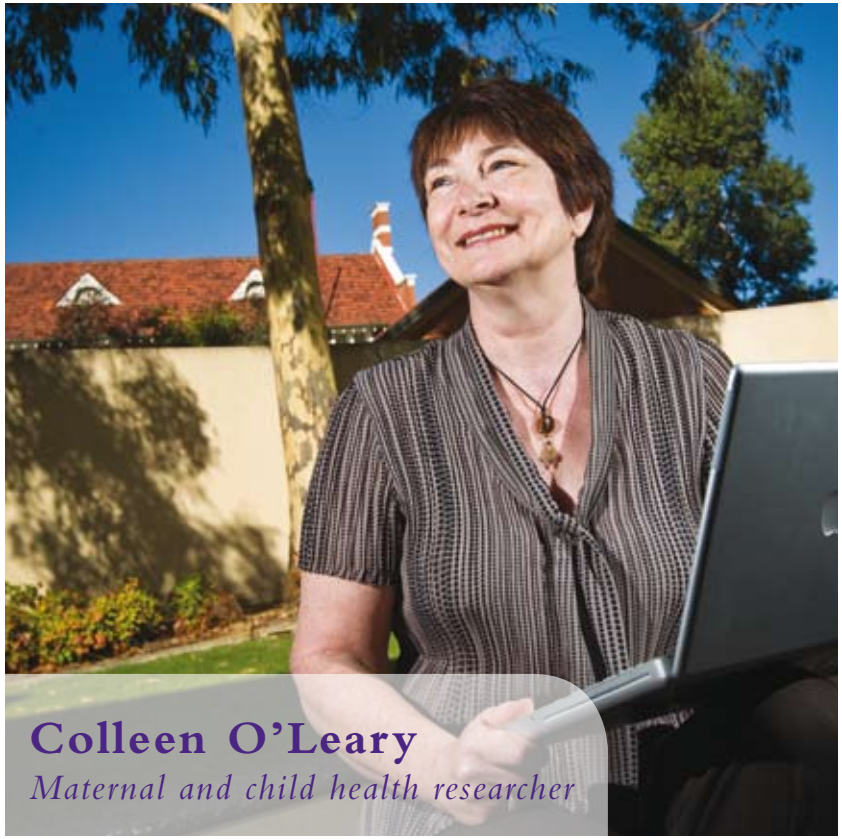
"We have local PNG staff including nurses and laboratory staff in the field, and in Perth I work with infectious disease experts including Dr Peter Richmond and Dr Deborah Lehmann," says Anita. "And I have to give a lot of credit to my two hard-working research assistants in the lab, Cath Devitt and Marie Nadal – they have been fantastic!"

Anita's role sees her travelling to PNG for two weeks every six months or so which is essential for the success of the study but does means she is away from her family.

"When I'm not working, I love spending time with Zuza (who is now five) and Maurice so it is hard to be away from them," explains Anita. "It's also challenging as we don't have the extended family support here in Perth. But we spend as much time together as we can - we especially love camping and seeing the world, and we all enjoy the laid-back Perth lifestyle!"

Anita hopes to soon complete the experiments and analysis for the PNG research and publish papers on this work, as well as see her PhD student, Joanne Lisciandro, submit her thesis. As to where Anita's career will take her in the long run, only time will tell. But she knows for certain that her future is in vaccine research in developing countries.

"In the end I hope to contribute to improving the health of children in the developing world by collaborating on immunisation trials that are aimed at showing the feasibility of vaccines and vaccine strategies in high risk populations," says Anita. "This is really important as vaccines are mainly designed in, and for, the developed world and hardly ever is their feasibility tested in populations in developing countries, where they are really needed – I hope to change this pattern!"



Colleen O'Leary

Maternal and child health researcher

Colleen started her working career as a nurse, but has always had an underlying interest in science and scientific research.

"After I married, my husband encouraged me to follow my dream of studying at university and so I enrolled at UWA to study science," says Colleen.

"I majored in biochemistry and physiology and after my degree I was lucky enough to work for Professor Pat Holt in asthma research for a few years, which I really enjoyed."

Colleen then took a few years off to raise her children but when the youngest started school she was quickly back into research and commenced a Masters of Public Health degree at UWA whilst working part-time as a coordinator of clinical stroke trials.

"After I completed my Masters, I worked as the project officer for the National Expert Advisory Committee on Alcohol (NEACA) and gained wonderful experience in alcohol policy development and advocacy at the national level," explains Colleen.

"It was due to the work of NEACA that alcohol and pregnancy and Fetal Alcohol Syndrome (FAS) was included on the national policy agenda in Australia, something I was proud to say I had contributed to."

Following other roles in the Health Department including a project officer position in the Child and Youth Health Network, Colleen joined the Institute as a research associate in 2005 under the leadership of Professors Carol Bower and Fiona Stanley.

"During my initial year at the Institute, I was a member of the Alcohol in Pregnancy research team which followed on from the work I had previously performed at NEACA. I still found it extremely interesting and when Carol Bower suggested I undertake a PhD on the subject, I didn't think twice!" she says.

Colleen enrolled for her PhD through UWA in early 2006 and is hoping to complete it some time in 2009. Her studies investigate the association between low to moderate prenatal alcohol exposure and fetal and child outcomes using data from the Western Australian Survey of Health (known as the RASCALS study).

"So far, I have looked at levels of language delay in babies born to mums who consumed alcohol during their pregnancy," explains Colleen.

"Our data showed a three-fold increased risk of the likelihood of language delay in children whose mums drank at binge levels in late pregnancy."

"Also, I have looked at the birth weights and numbers of pre-term babies and found that pre-term births increased with higher levels of prenatal alcohol exposure. Even mothers who consumed alcohol early on but ceased before their second trimester had more pre-term births than those who abstained for their whole pregnancy."

Colleen has authored six peer-reviewed journal articles since 2005 and in 2007 her efforts were rewarded when she received the inaugural Dr Louisa Alessandri Memorial Fund Prize for Best Scientific Publication.

"This was a nice surprise, and I felt proud to be recognised for the hard work put in by not only myself but all the co-authors of the paper," says Colleen.

Colleen's results on the effects of prenatal alcohol exposure have already helped to guide government policy. In early 2009, new national guidelines for alcohol consumption during pregnancy were released, stating that avoiding alcohol is the safest choice for women who want to ensure that their babies are not affected by alcohol before birth.

There is no doubt that Colleen feels she has found her niche in medical research and she plans to continue her current work at the Institute in the future.

"My immediate goal is to complete my PhD by the end of 2009 and then to find funding to continue my research into alcohol and pregnancy," she says.

"I'm awaiting data from the Data Linkage Unit for a project to investigate the health outcomes for women who have an alcohol-related diagnosis recorded during pregnancy, and their children."

Outside research, family plays an equally important part in Colleen's life and she cites raising her children as her greatest achievement to date. She also knows that they are very proud of what she is doing and support her 100 per cent along the way.

"My passion is to improve the lives of children who are exposed to parental alcohol misuse, to raise awareness in the community about the harms related to alcohol, and to change alcohol policies to support responsible drinking – this is what drives me to do what I do."

Finance and business development

The financial summaries towards the end of this annual report, combined with the overviews of our research activities, will indicate that the Institute performance was robust. Our success in winning research grants and contracts reflects the depth and breadth of excellence for which we are known.

That is not to say we are without challenges and I believe we stand at a critical point in the life of the Institute in terms of our capacity to meet the needs of the future. The issues we face are not dissimilar to any other business. We need to remain competitive, retain and attract the best people and attain financial security.

Financial capacity and security sits at the core of our activities. In this regard there are several key issues - one is the inadequacy of research grants to provide for competitive salaries and another is the funding of research support. Both issues stem from research funding agencies not recognising the full cost of research. Salary levels inherent in grants from, for example, the National Health and Medical Research Council, fall at least 20 per cent short of research salary benchmarks. In addition, they contain no provision for the infrastructure required to support the researcher.

These issues are major rate-limiting steps not just for this Institute's ability to retain, attract and support medical researchers into the future but for the State and the country as a whole if it is to reclaim its position in the world of innovation. In conjunction with other medical research institutes at both a local and national level, we are making every effort to bring the significance of these matters to the attention of the State and Federal Governments.

Related to this is the support provided to us from the State Government, which is linked to our success in winning competitive, peer-reviewed grants. I refer to the State Government's Medical and Health Research Infrastructure Fund (MHRIF), which is critical to our existence. Its initiation by previous Governments and its continued support by the present Government are to be applauded. However, in real terms the fund has been declining consistently for four years despite the return on investment being comfortably more than 10-fold when measured against the income attracted into the State for medical research. This is another matter upon which we liaise closely with State Government.

In the meantime, in order to remain competitive the Institute is investing a significant amount of its own financial resources into its people and support services in the expectation that eventually the quantum of external grant funding will more adequately cover the full cost of research.

The financial resources to which I refer are primarily the funds we have raised from the public via our philanthropic fundraising efforts. These funds are accumulated in our 'Children's Future Fund' and are used to generate an income stream to enable us to be strategic and also to cushion the effects of some of the challenges noted above. I would like to make particular mention of Channel 7's Telethon and of course the people of Western Australia who support that event. Over the years it has been a significant contributor to our endeavours, for which we are very grateful.

The added challenge that affects us all at present is, of course, the global economic crisis. As would be expected it is adversely impacting on most sources of income and, in particular, our income for research support, donations into our futures fund and the income we can generate from it. Our operating costs and future cash flows are being closely monitored and our primary aim is to maintain staff stability for as long as possibly without irreparably damaging our financial position. If we can achieve this then we will be all the stronger once the economic crisis has passed us by, which it will inevitably do.

As we look to the future, we have a major opportunity to grow our research activities as part of the redevelopment of the QEII site in Nedlands. The State Government has committed to the relocation of Princess Margaret Hospital (PMH) to that site. We are currently collocated with PMH because of the extensive collaboration between hospital-based clinicians and researchers and the researchers at the Institute. It naturally follows that if the hospital is to relocate then we must seriously contemplate following suit if we are to maintain that strong linkage.

The additional opportunity that flows from this relocation is the close proximity we will have with other research organisations, the majority of which will be represented on the QEII campus. Rarely has this been achieved in any other part of the world and so the chance to share knowledge as well as achieve economies of scale is unparalleled.

We are currently in the early stages of planning this move and, not surprisingly, money is a key factor determining what we can build and by when. As our existing facility is now more than fully occupied, the prospect of additional facilities on the QEII site is timely.

As you might imagine from all the challenges and opportunities that face us, only a handful of which have been highlighted in this report, the team that supports the Director, myself and others need to be, and are, dedicated, dependable and of the highest standard. It's a pleasure to be part of that team and I thank them all for their support.

Finally, I'd like to make particular mention of Robert Ginbey who, since 1995, has headed the administration and corporate services activities at the Institute. Robert retires in May 2009. In reality his impact and influence across the Institute spans far more than administration and corporate service activities. To me and many others, he is a wise counsel, a confidante and a friend. I wish him a long and happy retirement.

Bruce McHarrie
Director of Finance and Business Development

Commercialisation and biotechnology

One of the key challenges in the commercialisation process is overcoming the 'commercialisation gap.' This refers to the financing gap that exists when a technology has progressed beyond the funding criteria of academic research funding agencies, such as the National Health and Medical Research Council, but is too early in its development to attract venture capital and other commercial sources of funding.

In early 2008, Western Australia became part of an initiative that had commenced in Victoria and New South Wales during the previous year to address the commercialisation gap. This initiative is the Medical Research Commercialisation Fund (MRCF), a $30 million fund formed from investments from Statewide Superannuation and Westscheme and managed by Brandon Capital, an experienced biotechnology venture capital team. The MRCF provides its member institutes with access to risk-tolerant investment funds for proof-of-principle experiments as well as for the formation of new companies.

For institutes to become members, it also requires the financial support of the institute itself and the relevant State Government. From Western Australia, this Institute along with the WA Institute for Medical Research joined the MRCF and we are very grateful to the State Government of the day, via what was the Department of Industry and Resources, for being supportive of this national initiative. Apart from the possibility of attracting investment funds for commercial initiatives, membership of this fund provides another avenue of interaction between medical research institutes across the country and from a Western Australian perspective helps to keep us involved in the national scene.

The Federal Government also plays a key role in the development of the biotechnology industry in Australia in many ways, such as the provision of development capital. The Investment in Innovation Fund (IIF) is an example, as well as the recently announced follow-on funding for the IIF. The sudden abandonment of the commercial ready scheme with little to no consultation was less helpful to the industry and those who play a role in it, such as medical research institutes. A spin

out of this Institute, Phylogica Ltd, has been the beneficiary of such a grant and there is no doubt that it would not be as well advanced if it had not been for the commercial ready grant. Arguably, its very existence today would have been questionable if it had not won such funding. I urge the Federal Government to continue with schemes of this nature.

The Institute has generated 37 patent families since its inception. As part of the commercialisation process, a number have been either licensed or assigned to third parties and others have been discontinued. The patent portfolio currently contains seven active patent applications that constitute our 'work in progress' of which one is at the provisional stage, another at PCT and five are in national phase.

A summary of the commercial opportunities and activities at the Institute is as follows:

Cancer

Our division of Children's Leukaemia and Cancer Research, headed by Ursula Kees, has identified a set of genes that discriminates pre-B ALL patients with a poor prognosis. The gene classifier predicts patient prognosis better than the current risk assessment factors of age and white blood cell count.

The Division has also developed a high-throughput real-time quantitative PCR method to detect very accurately a specific type of gene deletion which has traditionally been very hard to establish unambiguously. Gene deletion can indicate a predisposition to developing disease or be an independent indicator of prognosis.

Asthma / Allergy

Researchers, headed by Pat Holt in the Division of Cell Biology, have identified a suite of genes that could provide a method of diagnosing and predicting the development of, and monitoring the treatment of, an allergic disorder. Additionally, these genes could provide a means to screen for potential agents to treat or prevent an allergic disorder or may be targets for the development of such agents.

Respiratory System Function

Airway function is the focus of an invention being developed in the Clinical Sciences Division by division head Peter Sly and others. The invention is a device to measure airway activity and its purpose will be to detect the early development, diagnose and monitor the treatment of respiratory disease. As an added feature, it is expected that the device will have application to infants, enabling measurement of respiratory activity without sedation.

Viral Infections

A large number of RNA viruses (including Hepatitis C) 'hi-jack' cellular translation machinery to prevent cellular protein synthesis and enhance translation of viral proteins. Existing drugs and vaccines are of limited use against RNA-based viruses since the high rate of mutation can circumvent very site-specific treatment methods.

Researchers at the Institute have developed a method of screening for peptide inhibitors of viral translation that will interact over a large interface of the viral RNA, therefore reducing the chance of mutation based resistance.

Contract Research

The largest component of our commercialisation activities would be classified as contract research. Of particular note are the activities of the Vaccine Trials Group (VTG), which has grown in significance over recent years.

The VTG was established in 1999 as a collaborative venture involving the Institute, Princess Margaret Hospital for Children and The University of Western Australia School of Paediatrics and Child Health.

The VTG's role is to provide a coordinated approach to the development, delivery, assessment and promotion of vaccines and allergy treatments in the community. It is involved in epidemiological studies, clinical trials of new and existing vaccines and in basic laboratory research necessary to design new vaccines.

The pharmaceutical companies involved with the VTG include Glaxo, Aventis, CSL, PPD and Wyeth.

Phylogica

Institute spin-out company Phylogica, formed in 2001 and listed on the Australian Stock Exchange in March 2005, is focused on the discovery of new drug opportunities using its patented peptide drug discovery engine, based on libraries of protein fragments.

The underlying technology aims at blocking the interaction of proteins that are involved in the disease pathway at the cellular level without disrupting the healthy interaction of other proteins.

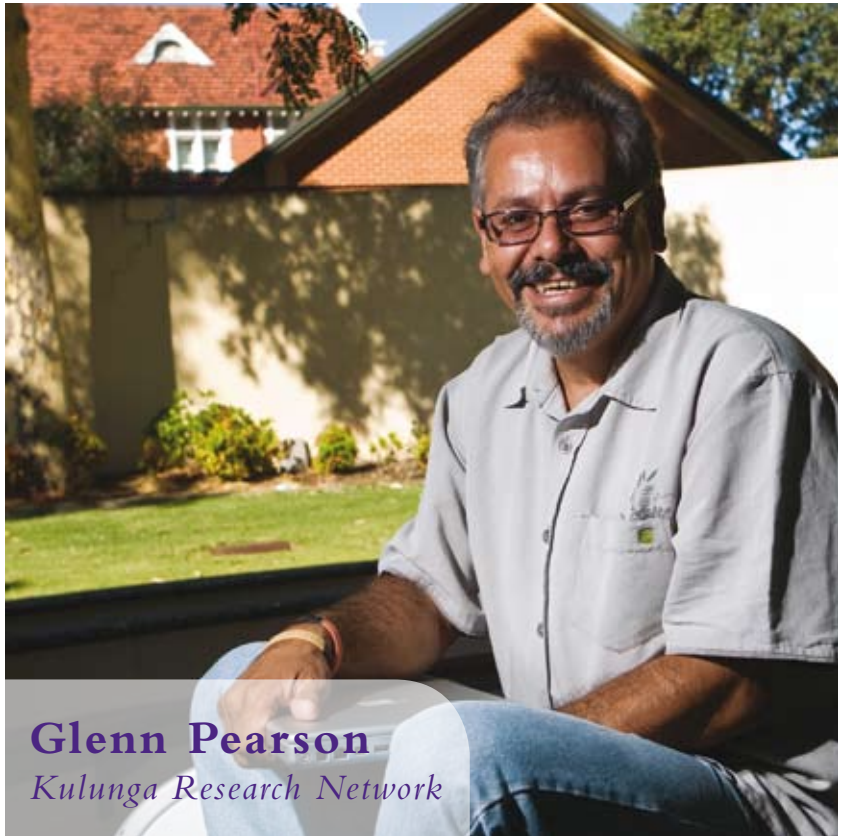
The Institute's current shareholding is approximately 10 per cent.

Advanced Diagnostic Systems

Our second spin-off company is Advanced Diagnostic Systems Pty Ltd (ADS), formed in 2003, is focused in the development of an asthma and allergy prognostic and diagnostic system. Funding was obtained from a UK-based investor and the Institute assigned the relevant patented technology into the company. The research work has concluded and the results have been very positive. However, to date, securing a commercialisation partner is yet to be achieved.

The current Institute shareholding is 45 per cent.

Bruce McHarrie
Director of Finance and Business Development



Glenn Pearson

Kulunga Research Network

Glenn Pearson is a proud father, a proud Noongar and a proud Fremantle Dockers supporter who one day dreams of a purple-coloured premiership. He is also one of the busiest people at the Institute, juggling his role as acting manager of the Kulunga Research Network with the demands of a PhD.

"I have always thrived on being busy – I figure I'll have time to relax later but at the moment, there is so much I want to achieve," says Glenn.

Glenn grew up in Perth wanting to be an air force pilot from a young age, but became a primary school teacher. However, after graduating from university with a teaching degree, the first 15 years of his professional career were spent away from the classroom in positions within the Federal and State Governments in a range of areas including health, education and social welfare.

"I have been directly involved in the design and delivery of a range of government initiatives including the Building Blocks Early Years 0-8 Strategy, the Aboriginal School-Based Traineeships, the WA Government's Justice Agreement as well as being involved in the WA State Government's response to the Gordon Inquiry," explains Glenn.

During this time, Glenn was a member of the secretariat to the Aboriginal and Torres Strait Islander Commission for four years. He was also involved in several reference groups engaged in high level negotiations to bring about improved circumstances for Aboriginal children, families, and communities.

"Being Noongar, I have always had an interest in improving the circumstances of Aboriginal people," says Glenn.

"I don't personally believe that we have to accept the things that happen around us or the role that we are cast as the one that you are stuck with for life - I'm interested in working out what stops us or helps us to be the fantastic things that we are for ourselves and for our families and communities."

This has been a common theme for Glenn throughout his career, and continues in his work at the Institute. He joined the Institute in 2005 as part of the WA Aboriginal Child Health Survey team which produced four volumes of survey findings, with Glenn contributing to the analysis, writing and communication of three of these volumes.

"I believe that this study went a long way to providing us with a lot of information that will help us to develop preventative strategies that promote the healthy development of Indigenous kids - I was proud to play a role in that," says Glenn.

In 2006, Glenn enrolled in his PhD which will explore how the delivery of health, education and child protection services provided by the WA State Government to Aboriginal clients is mediated by the perceptions that non-Aboriginal and Aboriginal people hold of themselves and each other in the provision and receiving of these services. However, Glenn is quick to point out that his research is not purely restricted to the Indigenous community.

"While my research is concerned with the improvement of the circumstances of Aboriginal families, it is also focussed on improving the circumstances of those who deliver these services - non-Aboriginal people," explains Glenn.

"I think that what I do in seeking to improve the circumstances of Aboriginal people and their families has equal merit in improving the circumstances of all families in the State."

For two days a week, Glenn is Acting Manager of Kulunga which aims to build the capacity for Aboriginal people to conduct research and training into Indigenous health issues. Glenn took on the role at the end of 2008 and he is involved in all aspects of Kulunga, including managing corporate partnerships and steering the direction of the research.

"We have three major projects currently underway with more in the pipeline so there is a lot to keep a handle on, but I have a fantastic team supporting me - without them, Kulunga would not be the success story that it is," Glenn says.

In the short term, Glenn wants to finish his PhD but he always has the future in mind.

"In the long term I want to grow some more research muscle around my current abilities to be a brilliant researcher and social scientist. I also want to have a blend of teaching the next generation of researchers and be involved in some form of practice, where I can apply the learning and stay connected to the reality of what is happening on the ground so that I stay true to it in my research."

Despite his busy lifestyle, Glenn never loses sight of the reasons behind his decision to pursue research, and uses these as motivation to keep working hard.

"The most important part of my life is my family and children. They remind me that what we do today can have a very powerful effect on the next generation...that the values that we have at the dinner table can live through to your grandchildren's lives. Their stories at the end of the day remind me of why we do what we do as researchers."

Risking Our Kids

It's not every day that a research organisation gets to highlight its work and its ambitions to a prime time audience on the ABC. That was the wonderful opportunity presented by documentary maker Jennifer Lee Lewes.

Jennifer, a well known film maker from New Zealand, has a long established friendship with Institute Director Fiona Stanley. After many conversations over the years, Jennifer was fascinated by stories about the Institute and the innovative nature of its scientific program.

After an intense period of research at the Institute talking with scientists and study participants, Jennifer plotted out some key story lines. Well respected production team RymerChilds were hooked on the concept and, along with Perth-based Thunderbox Productions, set about turning the concept into reality.

At the start of 2008, funding had been secured with the support of ScreenWest, and it really was a case of 'lights, camera, action!'

The crew, headed by experienced Director Judy Rymer, spent four weeks filming around the Institute and at locations from Port Hedland in the north to Denmark in the south of Western Australia.

For Fiona Stanley, it was a rare chance to reflect on the Institute's success, as well as look ahead to the important work that needs to be done.

"What was fantastic about the film makers was that they really understood and became passionate about how high quality research can serve a human rights agenda by prompting action," Professor Stanley said.

"We were really able to show, in a very engaging way, the importance of data and evidence and how improvements in health outcomes may depend on strategies in a range of other areas such as economic inequalities, the workplace, education and housing. It's not often we get to discuss publicly these complex factors."

Documentary director Judy Rymer said making the film was a privilege and challenge.

"The trifecta of internationally acclaimed scientist, political advocate and engaging communicator is very rare," Ms Rymer said.

"Combine that with a fearless passion to protect the nation's children and you have someone who makes compelling viewing."

The documentary screened in October at 8.30pm on ABC TV. It was also given a special parliamentary screening, hosted by the Parliamentary Secretary for Early Education and Childcare, Maxine McKew.

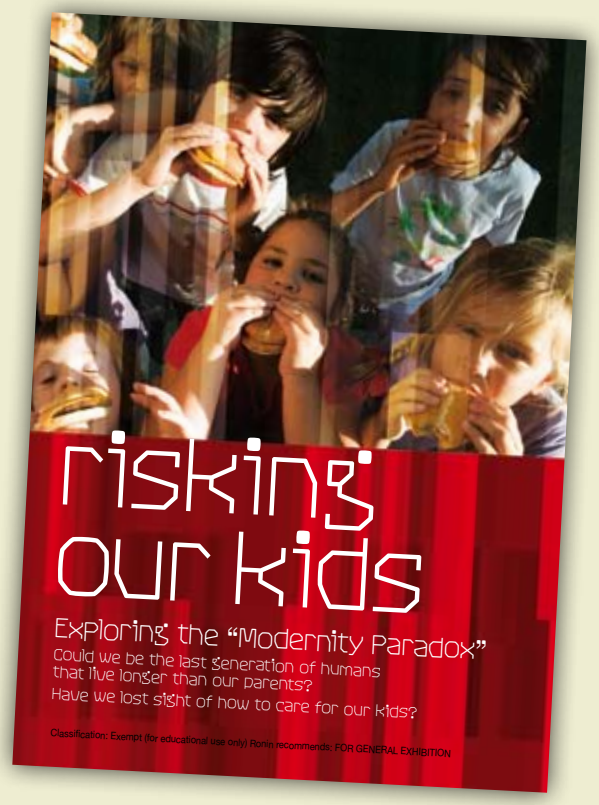
Professor Stanley said the response to the film was overwhelming.

"Many people found the information in the film about the declining outcomes for children in Australia to be quite confronting," she said.

"But it moved them to want to know what they could do, what governments and businesses could do to make sure that our children are beneficiaries of our society and not compromised.

"It's an important message and I am so grateful to Jennifer Lee Lewes, Judy Rymer, Bevan Childs, Jody Nunn and all the dedicated film team for putting our Institute's mission on the national stage in such a compelling way."

Copies of the film and an education study guide are available through the distributor www.roninfilms.com.au



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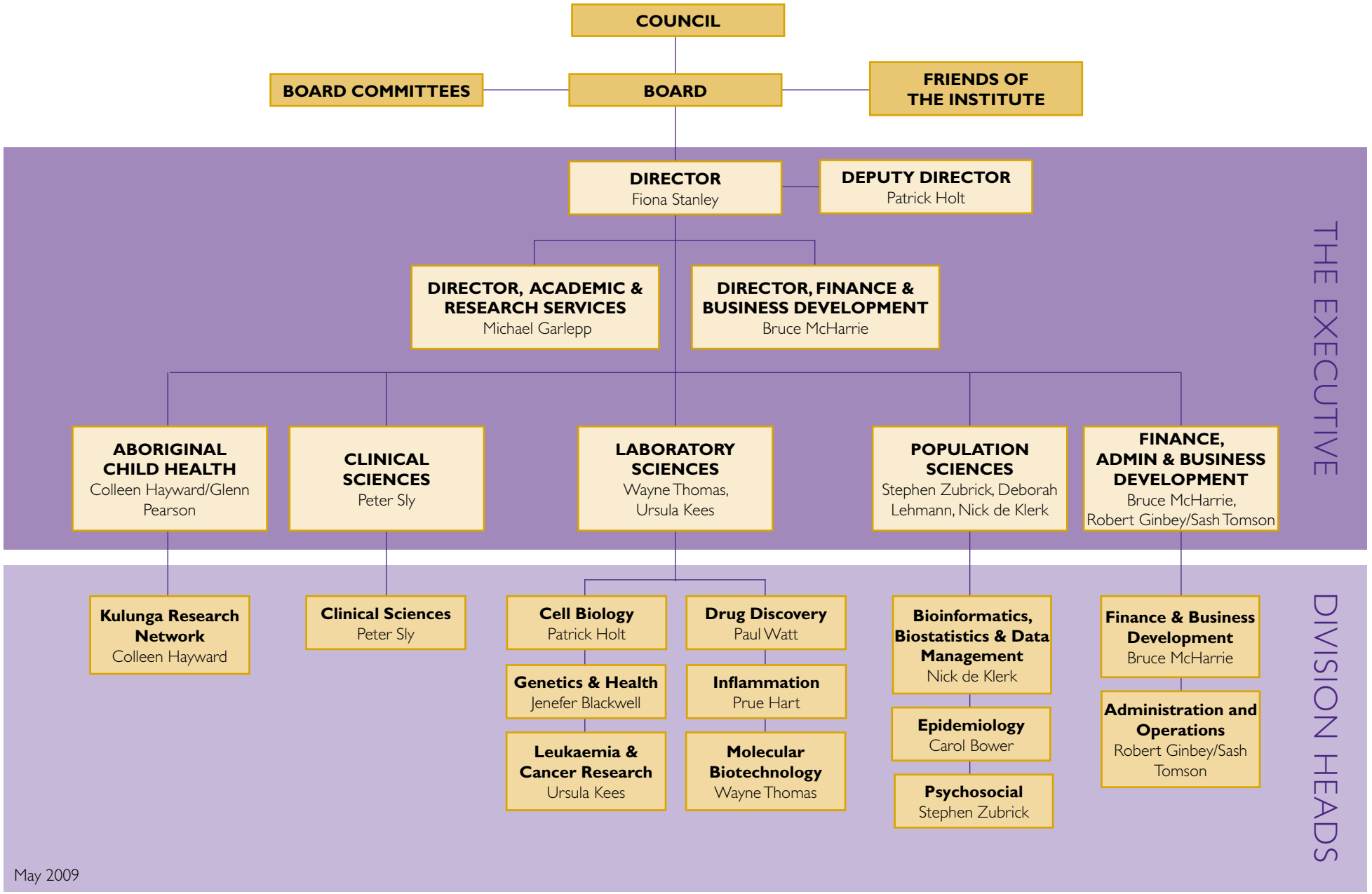


Olivia White

PhD student

Olivia White was 12 when she knew she wanted to be a medical scientist. During a school excursion to a pathology lab, the students were asked to cough into an agar dish and a week later they looked at the results.

"I was always sick so mine grew heaps of bugs," explains Olivia. "I thought that was really interesting and since then I knew I wanted to do research, that would be my way of helping people."

"I wanted to invent 'The Little White Pill' that would cure cancer and AIDS and I would make it free for everyone."

True to her word, Olivia gained her Bachelor of Science at the University of Queensland followed by an Honours project studying human papilloma virus (HPV), the virus that causes cervical cancer. She then worked on HPV vaccine trials for Professor Ian Frazer, 2006 Australian of the Year and co-inventor of the HPV vaccine.

"Ian Frazer was a fantastic boss, and to be a part of his team and see the hard work actually making a difference to peoples lives is what makes it all worthwhile," says Olivia.

Whilst working in Brisbane, Olivia met her fiancé Angus, who was completing his PhD in Immunology and finishing his post-graduate medical degree. After Angus graduated, he was offered an intern position back in his native WA and in 2005 they re-located to Perth, a move that signalled the need for Olivia to find a new place to pursue her research career.

"I was told about the Telethon Institute by a colleague in Brisbane and of course, I'd heard all about Professor Fiona Stanley when she was named Australian of the Year in 2003," explains Olivia.

"The more investigating I did, the more it sounded like the obvious place for me to continue my medical research in Perth and when I saw the building and met some of the researchers, I was hooked!"

Olivia began work in the Institute's Division of Clinical Sciences working on animal models of asthma, which are vital tools in the ongoing research into this common childhood disease.

"I have always battled with asthma, so this project was especially relevant to me and my family," she says.

But Olivia's passion for vaccine research was still as strong as ever, and before long she had accepted a position as research assistant in the Institute's Vaccine Trials Group, headed by vaccine expert Dr Peter Richmond.

"I was really excited to get back into vaccine research, particularly as one of the VTG's clinical studies involved the HPV vaccine. But there were also other vaccines being trialled that I became interested in, and when the opportunity arose to do my PhD on the whooping cough vaccine being supervised by Pat Holt and Peter Richmond, I didn't think twice!"

Whooping cough, also called pertussis, is a highly infectious disease that affects both children and adults. It is spread by coughing and sneezing and in Australia more than 4,000 cases of whooping cough are notified each year.

"Young children under 12 months of age are the really susceptible ones," explains Olivia. "Currently, babies get their pertussis vaccine at two, four and six months and a booster at age four, but they really aren't fully protected against the disease until at least four months old. That means that before this time, babies are at greater risk of contracting whooping cough which can make them very sick and in the worst cases, it becomes fatal."

Olivia's project involves babies receiving the whooping cough vaccine at birth in addition to the regular doses at two, four and six months. The babies were recruited through Sydney's Westmead Children's Hospital and the Women's and Children's Hospital in Adelaide and blood samples from the children were sent to Perth.

"The aim of my project is to look at whether there are any safety issues with giving the whooping cough vaccine at such an early age and whether the newborn babies' immune system is mature enough to respond to the vaccine," she says.

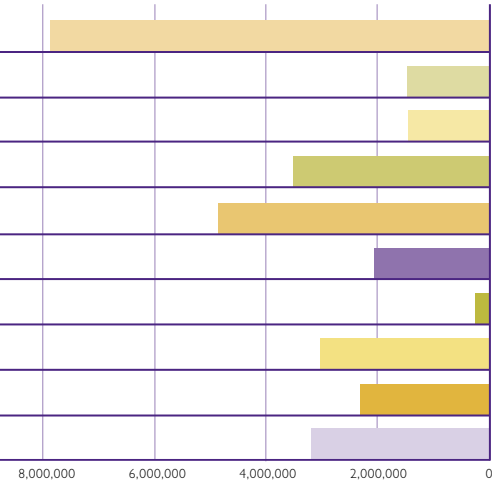
Now in the final year of her studies, Olivia's next goal is to publish her data and submit her thesis. In the long-term, she hopes to find a specific area of infectious disease research that she is passionate about and become an expert in that field.

"The best thing about research is that when you have a question you wish to answer and you work in the lab doing your experiments and you get that answer, sometimes it's an answer that will help the community in some way. That can be a real thrill!" says Olivia.

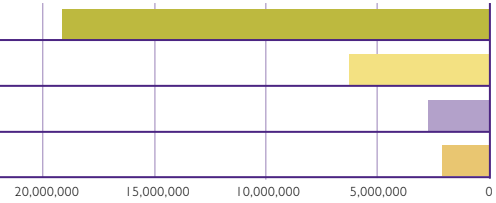
Outside of the lab, Olivia's other passions are her beagle Rocket, reading, cooking, wine-tasting and following her beloved Queensland Reds rugby union team, although she has recently been seen cheering on the Western Force at Subiaco Oval!

2008 - The year in brief

INCOME	Amount	%
Australian competitive grants	7,891,685	26.2
International competitive grants	1,489,413	4.9
Other competitive grants	1,475,511	4.9
Government contracts	3,533,201	11.7
Commercial income	4,869,624	16.1
Other grants	2,076,456	6.9
Miscellaneous income	265,515	0.9
Donations, fundraising, bequests & sponsorship	3,036,702	10.1
Investment income	2,326,290	7.7
Research support	3,198,825	10.6
Gross income	**30,163,222**	**100**
Deferred income	(2,297,034)	
Net Income	**27,866,188**	



EXPENSES		
Scientific research	19,112,739	62.8
Research administrative and building services	6,319,312	20.7
Impairment of investments	2,851,304	9.4
Depreciation and provisions	2,175,843	7.1
Total	**30,459,198**	**100**



SURPLUS (DEFICIT) **(2,593,010)**

Staff and students

Total number of staff as at December 31 (paid and seconded) - 368

An increase of 4.8% (up from 351) in 2007

Total number of postgraduate students during the year - 100

An increase of 17.6% (up from 85) in 2007

Total staff and students in 2008 - 468

An increase of 7.3% (up from 436) in 2007

Total number of honorary and visiting scientists during the year - 77

An increase of 10% (up from 70) in 2007

Research income

Australian Competitive Grants	
Arthritis Australia	45,000
Australian Research Council	219,823
Cystic Fibrosis Association	148,097
National Health and Medical Research Council	7,448,593
National Heart Foundation Australia	30,172
	7,891,685
International Competitive Grants	
Autism Speaks Inc	73,086
Canadian Institute for Health Research	15,620
Cystic Fibrosis Foundation Therapeutics	42,108
International Rett Syndrome Association	76,060
Miscellaneous overseas grants	4,226
National Institutes of Health	1,054,970
Offord Centre for Child Studies	24,156
Wellcome Trust, UK	181,055
World Health Organization	18,132
	1,489,413
Other Competitive Grants	
Asthma Foundation of Western Australia	10,158
Cancer Council Western Australia	260,684
Child Health Research Foundation	101,643
Children's Leukaemia and Cancer Research Foundation	492,574
Healthway	351,262
Raine Foundation	259,190
	1,475,511
Government Contracts	
Western Australia	
Department of Child Protection	156,429
Department of Education and Training	94,478
Department of Health	1,516,329
Department of Indigenous Affairs	4,575
Department of Industry and Resources	125,000
Department of the Attorney General	36,714
Disability Services Commission	77,169
Office of Science and Innovation	34,818
Federal	
Australian Agency for International Development	20,020
Department of Family, Community Services and Indigenous Affairs	120,000
Department of Health and Ageing	1,359,790
Miscellaneous	263
	3,533,201

Commercial Income	
Alcoa	125,000
ALK-Abelσ A/S	88,000
Baxter Healthcare Pty Ltd	37,515
BHP Billiton Australia Limited	77,258
Chevron Australia Pty Ltd	9,999
CSL Limited	746,498
Dynamic Microbials Pty Ltd	156,553
GlaxoSmithKline Australia Pty Ltd	191,598
GlaxoSmithKline Services Unlimited	55,244
Merck Sharpe & Dohme (Australia) Pty Ltd	84,439
Miscellaneous	3,386
OM Pharma	30,007
Phylogica Limited	1,543,486
Pilbara Iron Company (Services) Pty Ltd	500,000
Sanofi Pasteur	129,285
Shell Australia Pty Ltd	300,000
Wyeth Australia Pty Ltd	330,214
Wyeth Pharmaceuticals Inc	461,141
	4,869,624
Other Grants	
Alcohol Education & Rehabilitation Foundation	51,295
Australian Council of Educational Research	11,169
Australian Research Alliance for Children and Youth	70,910
Australian Respiratory Council	48,563
Curtin University of Technology	257,494
Edith Cowan University	24,440
Friends of the Institute for Child Health Research	22,136
McComb Foundation Inc	1,536
Miscellaneous	23,908
Mission Australia	7,273
Murdoch Childrens Research Institute	50,000
PMH/Women & Children's Health Service	13,103
Princess Margaret Hospital Foundation	25,655
Resource Unit for Children with Special Needs Inc	8,396
Royal Perth Hospital	5,137
The University of Western Australia	1,445,442
Western Australian Institute for Medical Research	1,200
Wunan Foundation Inc	8,800
	2,076,456
Miscellaneous income	265,515
TOTAL	**21,601,405**

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*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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Jette Ford

Cancer researcher

Danish-born Jette first started working in children's cancer research in 1984 as a research assistant in Professor Ursula Kees' lab at Princess Margaret Hospital. When the team joined the newly-formed Institute in 1990, Jette also made the move. So it was great sadness that the Institute farewelled Jette into retirement after more than 22 years in the position – only to welcome her back 12 months later!

"I started my retirement but found that I missed work so much that I thought whilst I am still healthy and still enjoy it, I may as well keep working!" says Jette.

Professor Kees was delighted that Jette had decided to put retirement on hold and immediately re-instated her in her old position in the Division of Leukaemia and Cancer Research and soon it was like she had never left!

Jette graduated from Curtin University with a Bachelor of Applied Science and Graduate Diploma in Computing, before commencing her position with Professor Kees.

During her career, Jette's main focus has been on childhood leukaemia and she has been responsible for developing a unique set of patient samples that has been vital to the Division's research.

"I have developed over 50 cell lines from children with leukaemia who have been treated at PMH," explains Jette. "These cell lines are very precious and have been used in our research and in many places around the world."

Leukaemia is the most common childhood cancer, affecting around one in 2,000 children in Australia each year. The cell lines that Jette has created start with bone marrow taken from the children, and they are then immortalised so they can be used in lots of different experiments, or frozen in liquid nitrogen for future work.

"In our lab, we use the cells to look at differences in gene patterns between different patients, and also between the leukaemia patients and healthy children's bone marrow," says Jette.

"We also used the samples to see why some patients' cells do not respond to certain chemotherapy drugs so we can improve the drugs that the children with leukaemia are treated with."

Jette is currently working on a project looking at the role of a specific gene called Connective Tissue Growth Factor in one of the forms of leukaemia known as Acute Lymphoblastic Leukaemia (ALL).

"Other studies have shown that 75 per cent of ALL patients have an unusually high level of this gene, so we are using the ALL cell lines to see whether this contributes to the growth and survival of the cancer cells."

Jette's wealth of experience has been a major asset to Professor Kees' team, as she regularly provides advice and support to her fellow researchers and in particular the new students who commence projects within the Division. She has seen many people come and go in the Institute as well as dramatic changes in how research is performed.

"Technology has improved and now we often use machines to perform the experiments which means we can do a lot more experiments in a shorter space of time," she says.

"That is a good thing but it can be quite challenging at times learning all of the new techniques."

Jette admits that research can be frustrating at times, particularly when experiments don't work. But on the other hand it can be very exciting, especially when she achieves good results.

"One of the highlights of my job is seeing my work being published in highly regarded medical journals, as well as seeing other researchers around the world using the cell lines that I created – it drives me to keep working hard!" says Jette.

Although Jette is a scientific thinker, she also has a creative side. When not in the lab, her favourite hobby is the craft of quilting.

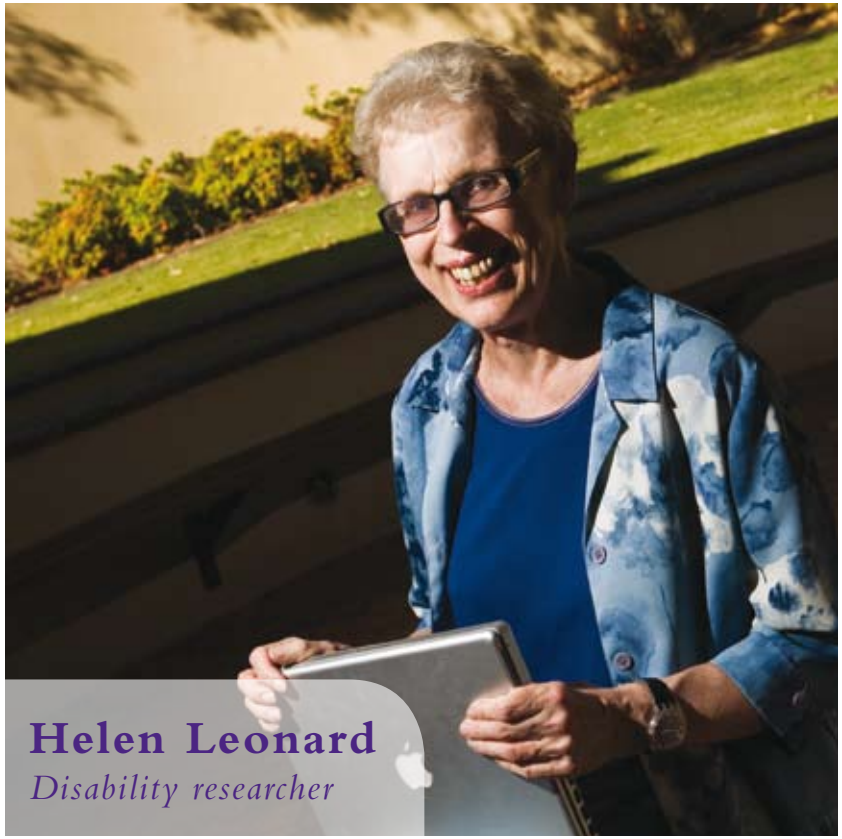
"I love designing and making art quilts - some are exhibited around the world and have won several prizes, which I am very proud of," she says.

Jette spends the rest of her spare time enjoying her three grandchildren and working out at the gym or going to the beach.

As for her future in research, Jette is philosophical and likes to take each day and its challenges, as they come.

"My goal is to stay healthy so I can keep working. I'm at that age now where you don't look too far into the future, but I don't think I am ready to retire again just yet!" says Jette.

"I would love to see a better treatment or even a cure for childhood ALL in my time, and that is what drives me to keep working hard."



Helen Leonard

Disability researcher

Dr Helen Leonard's interest in disability research was sparked during her work as a clinician in the WA Disability Services Commission during the 1980's and 1990's. Despite the important work that she performed in the clinical care of children with a disability, the experience also left Helen feeling frustrated that there was little emphasis on looking at the causes of these conditions.

"The clinical work brought up so many questions in relation to the causes of intellectual disability and rare syndromes that were not being answered in the literature and yet that I could see we had the potential to answer both through population-based research and the development of important registers," explains Helen.

Helen's desire to identify the reasons behind why some children are affected by disability led her to enroll in a Masters of Public Health degree in 1993.

Based at the Institute under the supervision of Professor Carol Bower, Helen chose to focus on a rare and complex disorder known as Rett syndrome, which affects one in 8,500 girls.

"At the time this was a mystery disorder which struck down little girls who, to all intents and purposes, were developing normally and would suddenly start to regress and yet no-one knew the cause," says Helen.

"Because there were only a handful of girls diagnosed in Western Australia with Rett syndrome, I knew that to be meaningful this had to be a national study to get a comprehensive picture of what the causes of this devastating disease were."

As part of her Masters degree, Helen established the Australian Rett Syndrome Database that has become a vital resource in the research of this rare disorder and has led to important support networks being developed for the families of these children. Helen was also instrumental in the formation of the International Rett Syndrome Phenotype Database which contains data from children all over the globe and which has facilitated the discovery of various genetic abnormalities associated with the disorder.

"The *MECP2* gene was originally identified as a gene that was abnormal in children affected by Rett syndrome," explains Helen.

"More recently, we published a paper showing that certain alterations in a second gene called *BDNF* could predict the disease progression of Rett syndrome - this in turn might be useful in deciding which treatment is optimal for the children displaying this version of the gene."

Helen's vision and commitment to Rett syndrome research was recently recognised with her being awarded the 2008 '*Circle of Angels Research Award*' by the International Rett Syndrome Foundation.

"I feel that this award and my recent achievement of an NHMRC Senior Research Fellowship really validates the importance of my research, whilst at the same time I feel totally privileged to be able to work with these families and be able to contribute to the global research effort for this disease," says Helen.

Along with Rett syndrome, Helen is also involved in studies looking at other childhood disabilities including intellectual disability and autism. Her studies have explored factors outside genetics that may increase the risk of children becoming affected by disability, including social and demographic elements.

"In relation to intellectual disability, Aboriginal mothers, teenagers, single and socio-economically disadvantaged mothers were all at increased risk of having a child with mild or moderate intellectual disability," explains Helen.

"These results show the need for further investigation into the causes as well as service provision for children with intellectual disability, as I believe all children in WA should have equal access to the best possible care available."

Helen says that one of the most difficult things about her area of research is securing funding, particularly as some of the disorders including Rett syndrome are rare. However, her passion for making a difference in the lives of the patients and their families helps her to maintain her focus.

"Basically, what drives me in my work is the question of how we can make life better for those affected and their families and even better, how we can prevent childhood disability in the first instance."

Despite her extremely busy schedule, Helen supervises a large number of students from Honours to PhD. She also makes a point of actively participating in all stages of the 'project cycle', from the family contact to family follow-up data collection, data management, data analysis and production of publications.

"I think it is extremely important to keep in touch at the grass roots level, to keep oneself grounded and to not forget the reasons why you're doing what you're doing," says Helen.

In maintaining a good work-life balance, Helen enjoys spending time with her beautiful grand-daughter, bushwalking with her dog and tending to her native Australian garden.

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