Improving the health and wellbeing of ...



PREVENTION INNOVATION DEDICATION



every child

Annual Report 2006

## 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 child health. Like the childhood illnesses and diseases we investigate, our team is diverse, consisting of some of Australia's, and the world's, leading experts in their fields.

We are housed in a purpose-built research facility on the edge of the Perth CBD and have close to 500 staff and students.

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.

### What we do

Our focus is on children, young people and their families.

We investigate the most complex, costly and devastating health problems facing our children in the 21st century. We approach these problems with dedication and innovation as we try to achieve our overall goal - prevention.

We work together. We work with others. We work hard to improve the life chances for all children.

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.

## Contents

2006 Highlights	4
International Scientific Review	7
Chairman's message	8
Board of Directors	9
Director's report	10
Research Review 2006	
Aboriginal child health	14
Asthma, allergies and respiratory disease	16
Cancer	18
Healthy development	20
Infectious disease	22
Social and emotional wellbeing	24
The early years	26
Understanding disability	28

Outstanding people	30
Collaborations and joint ventures	34
Consumer and community participation	37
Corporate and community partnerships	38
Chief Financial Officer's report	42
Commercialisation and biotechnology	44
Committees of the Board	46
Management/Operating structure	47
Administration and Corporate Services	49
2006 - The year in brief	50
Research income	51
Our supporters	52

## Every child



At the Telethon Institute for Child Health Research we know that many children suffer through childhood from poor physical or mental health and disadvantaged environments.

Our dedicated team of close to 500 researchers and staff are committed to unravelling the complex issues that are affecting the health and wellbeing of our children.

Our unique multidisciplinary approach means that we explore these issues from many angles -- what are the genetic, environmental, biological, social and economic factors that are affecting the physical and emotional development of children?

Why do some children grow strong while others are sick?

Why do some succeed and others struggle?

What does it take for a child to grow up healthy and happy?

The answers are important for every child, every family, every community.

Our research themes reflect our broad approach:

- Aboriginal child health
- Asthma, allergy and respiratory disease
- Cancer
- Healthy development
- Infectious disease
- Social and emotional wellbeing
- The early years
- Understanding disability

We believe that **every child** should be given **every chance** to reach their full potential

PREVENTION INNOVATION DEDICATION

every child ...

should know love

should be safe

should feel hope

should enjoy laughter

should be valued

should be filled with strength and energy

should have a childhood

Every one of us can make a difference to the



# life of every child.

## 2006 Highlights



Our total research income for the year was \$20 million.

In 2006, our researchers published extensively with 169 publications including research papers in national and international journals, books, book chapters, reports and special newsletters.

Our researchers presented their research findings far and wide, from Perth to Paris, Brisbane to Boston, Sydney to Saskatoon. We launched a world-first international research trial into a treatment that could prevent **asthma** in high-risk children. The treatment, developed by Institute Professors Peter Sly and Pat Holt, involves exposing babies and toddlers to tiny doses of common allergens as an oral vaccine to stimulate immune responses which protect against allergy. The trial is being led by the Institute with other trial sites including Melbourne, New York, Stockholm and Berlin. (see page 16)



**above:** *Institute researchers present their findings all over the world.* 

A new study showed that babies that are **breastfed** for longer than six months have significantly better mental health in childhood. The findings were based on data from the ground-breaking Raine Study, that has tracked the growth and development of more than 2500 West Australian children over the past 16 years. (see page 26)

Our Vaccine Trials Group began testing the effectiveness of a new vaccine to protect against the potentially deadly **bird 'flu**. Trials began in healthy adults and were extended to include older Australians and children. With no live virus in the vaccine, there is no chance of catching the infection from the vaccination, which had already been shown to be safe in initial trials. The adult trial showed positive results and the manufacturer, Australian company CSL, applied to license the vaccine in 2007. (see page 22)

We announced a world-first system for predicting the severity of **asthma** in young children. The system is being developed by research teams led by Professors Pat Holt and Peter Sly and will help doctors to more effectively tailor asthma treatments to suit individual children as young as 18 months. Critical tests that, when combined, will paint a very accurate picture of a child's asthma pathway, have been identified and will help determine which children will grow out of their asthma, and which need a more aggressive form of treatment to prevent the disease from developing to a serious level and persisting into the teen years. (see page 16)

We launched a trial for a new combination vaccine that aims to reduce the number of injections needed to protect children against **meningitis**. The vaccine, which is already licensed and being used in the United Kingdom, combines the *Haemophilus Influenzae* type b (Hib) meningitis and the Meningococcal C strain of meningitis into one injection. (see page 22)

Research findings from our LOOKING at Language study, the world's largest study predicting children's late language emergence, revealed that parents are not to blame for late talking toddlers. The project analysed the **speech development** of 1766 children in Western Australia from infancy to seven years of age, with particular focus on environmental, neurodevelopmental and genetic risk factors. Results show that 13 per cent of children at two years of age were late talkers, that boys were three times more likely to have delayed speech development, while a child with siblings was at double the risk, as were children with a family history of late talkers. (see page 20)

We analysed hospital records for children aged under two years in Western Australia and found admission rates for **meningitis** have dropped by more than 70 per cent between 1992 and 2000. The introduction of the Hib (Haemophilus influenzae type b) vaccine to the childhood immunisation schedule was the main reason for the dramatic drop. The analysis also showed that while the incidence of meningitis in Aboriginal children remained higher than the general population, the disparity in the rates had reduced. Further declines are expected once the impact of the recent introduction to the schedule of vaccines against some meningococcal and pneumococcal strains has been assessed. (see page 22)

Perth women contributed to a global study of an exciting new **Human Papillomavirus** (HPV) vaccine that could protect against cervical cancer -- one of the most common causes of cancer-related deaths in women worldwide. Healthy women aged between 26 and 45 years of age were recruited to the study to test the vaccine's effectiveness in a wider age range and in women who have already been exposed to HPV. The vaccine has since been licensed for girls and young women. (see page 22)



**above:** HPV vaccine study participant Louise is vaccinated by Dale while daughter Amelia looks on.

Researchers at the Institute have found that exposure to measured doses of ultraviolet light, such as sunlight, could reduce **asthma**. The team studied the effect of ultraviolet light on the development of asthmalike symptoms in mice, such as inflamed airways and lungs and found that exposure to ultraviolet light for 15 to 30 minutes before allergen exposure significantly reduces the development of asthma-like symptoms. (see page 16)

**left:** The asthma and sunlight research team of Professor Prue Hart (back) with Alex Kuritsky and Jacqueline McGlade.



**left:** Ernie Dingo and children from Montrose Primary School choir at the launch of Volume Three of the WA Aboriginal Child Health Survey.

We launched Volumes Three and Four of the Western Australian Aboriginal Child Health Survey. With a focus on education, Volume Three found little significant improvement in educational outcomes for children in more than 30 years with many of the programs to support Aboriginal **children** starting in late primary or high school, by which time the gap in performance between Aboriginal children and others is simply too great. The results from Volume Four concentrated on families and communities and showed that most existing intervention programs are failing to produce results needed for overcoming the present levels of Indigenous disadvantage. (see page 14)

A breastfeeding research project by Dr Wendy Oddy was recognised as one of the '10 of the Best' National Health and Medical Research Council-funded research



projects for 2006. Her research showed that babies that are exclusively breastfed for at least six months receive significant protection from the development of asthma and other respiratory illness.

Our researchers were part of the international team that found that the genetic flaw responsible for **Rett syndrome** can strike males, even where there isn't a family history of the rare brain disorder. The finding means that testing for the genetic disorder should be considered in some baby boys who develop progressive serious neurological problems. (see page 28)

Our Aboriginal swimming pools study concluded with final results showing significant health and social benefits for children. A big drop in **ear and skin disease** was recorded when children were swimming for sustained periods of time. In the community of Jigalong, between 2001 and 2005, there were reductions of 41 per cent in antibiotic prescriptions, 44 per cent in ear disease, 51 per cent in skin disease and 63 per cent in respiratory disease, when compared with the pre-pool rates.

**left:** Dr Wendy Oddy with Tony Abbott, Minister for Health and Ageing, and mum Wendy who breastfed her baby.

We began trials of a new vaccine that could potentially provide protection against the B strain of meningococcus, the most common form of the disease in Western Australia. There is currently no vaccine available to prevent

**Meningococcal B disease**, which accounts for 80 per cent of cases in WA. Children between the ages of one month and one year are most at risk from meningococcal disease with a second peak in adolescence. (see page 22)



**above:** Lachlan (left) is part of the trial of the new meningococcal B vaccine, which it is hoped will prevent the disease that affected James (right) when he was a toddler.

## International Scientific Review

"Many of the challenges that the Institute faces today are the challenges of success."

*"It [the Institute] could be ranked as the top-performing research institute of its size in Australia."* 

"The Telethon Institute for Child Health Research is a unique organisation and is highly successful in achieving its mission through integrating research in population, clinical and biological sciences with community engagement, involvement in public health policy and development and in advocacy."

> Report of the International Scientific Review Panel January 2007

In November 2006, the Institute held its five-yearly International Scientific Review, which involved an external panel of experts reviewing our performance over the previous five years and our plans for the coming five.

Institute Assistant Director Professor John Finlay-Jones said such a review was not only a reflection of our commitment to independent review, by peers, of the evidence of our performance, but an expectation of our stakeholders.

"As part of the expectations of the National Health and Medical Research Council for accreditation as an Independent Medical Research Institute, we have to undertake a periodic and detailed international scientific review of our research," he said.

"In this sense then, the Review has a formal place in our ongoing business timetable. Even without that formal requirement, we would arrange an independent five-yearly review as part of a commitment to quality assurance and external benchmarking in all of our activities."

Professor Finlay-Jones said that in preparing for the panel's arrival, the Institute undertook a detailed 'self-review' and prepared in-depth documentation of performance, outcomes and future plans.

"The report from the Panel was very positive about the way the Institute's programs as a whole reflected our mission."

"It complimented us on our achievements in our research programs and the way many demonstrated our aim to translate research into outcomes that included government policy, professional practice and, in some instances, commercialisation."

The recommendations of the Panel have prompted a fundamental set of questions about what the Institute should look like in five to 10 years, especially as we will see relocation of the Institute should the children's hospital move.

"The expertise of the Panel will assist in our scientific priorities and directions as well as addressing 'big picture' issues affecting the Institute," said Professor Finlay-Jones.

"Whilst the next major Institute review is another five years away, there's broad agreement that we should maintain the momentum established by the 2006 review, and build more detailed audits of performance and selfreview into our regular strategic planning sessions."

The review panel was Chaired by Professor Don Roberton from the University of Otago in New Zealand and included:

- Professor Nick Nicola from The Walter and Eliza Hall Institute of Medical Research in Melbourne
- Professor Ezra Susser of Columbia University in New York, USA
- Professor Craig Mellis from the University of Sydney
- Professor John Hopper from the University of Melbourne
- Ms Janelle Stirling, a consultant in Indigenous health research.

### Chairman's message



It is a daunting experience for any organisation to throw open its doors and its operations for intense scrutiny from a panel of international experts in the field. Yet that's exactly the process that the Telethon Institute has pledged to embrace every five years with an International Scientific Review to both reflect on the previous period and to make recommendations for future action.

The third International Scientific Review of the Institute was undertaken at the end of November. The members of the Board were very pleased for the opportunity to meet with the panel over the course of the review week, to participate in discussions of strategic matters for the Institute, and to have panel members join us during Board Committee proceedings.

I am very pleased to say the results were outstanding as evidenced by these comments from Review Chairman, Professor Don Roberton, in the Panel's report:

"The Panel believes the Institute can consider itself to be performing at the highest levels internationally in terms of its leadership, its research programs, its publication outputs, its competitive grant successes, and its role in translation of its research findings to practical and achievable improvements in health outcomes for children and young people.

The Institute has much to be proud of. It has an exciting future, and will continue to grow. It will have a very important role in assisting with the development of appropriate state

### based, national and international children's agendas in the immediate and longer term future."

On behalf of the Board I would like to congratulate Professor Fiona Stanley, staff and students at the Institute on an exceptionally good outcome – as judged by their peers.

Of course the important work that is undertaken by the Telethon Institute simply couldn't happen without the generosity of so many corporate partners, donors and sponsors. We are particularly grateful for the continued support from Channel 7's Telethon and the people of Western Australia. We value our partnerships with major donors including Alcoa, Stan and Jean Perron, QANTAS, Rio Tinto, Shell and Wesfarmers.

I'd also like to acknowledge the continued support of the Commonwealth Government and the Government of Western Australia in funding both research and importantly, infrastructure and capital works – particularly as we plan for relocation along with Princess Margaret Hospital for Children.

We continue to enjoy a close alliance with The University of Western Australia through the Centre for Child Health Research, and with Curtin University of Technology through the Centre for Developmental Health. In the past year our collaborations with other universities have continued to grow, including Edith Cowan University, Murdoch University and Notre Dame.

Thank you to our honorary auditors, KPMG, for their services again this year. Our appreciation also goes to Deloittes for risk management advice when called upon.

Finally I'd like to extend my gratitude to the Board for their commitment and inspiration throughout the year. We have been privileged to welcome a new appointment to the Board in Dr Jackie Huggins AM, Deputy Director of the Aboriginal and Torres Strait Islander Studies Unit, University of Queensland.

However I must also report that after 15 years of dedicated service, Mr Harvey Coates AO has indicated he will step down from the Board in 2007. His contribution towards the development of this Institute is immeasurable, and he will be missed.

My personal thanks goes to all Board members and to those who contribute in a voluntary capacity to Board Committees, and to the ongoing work of the Institute. We share a common vision to improve and promote the health and wellbeing of all children and their families. And according to the report by the International Review Panel, we're not only making a difference, we continue to be at the cutting edge of child health research.

#### Kevin Campbell AM

## Board of Directors



**Top row, left to right:** Kevin Campbell, Harvey Coates, Jackie Huggins and Keith Jones. **Bottom row, left to right:** Jenni Ker, Louis Landau, John Langoulant, Graham Mitchell and Fiona Stanley.

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 (see page 46).

Kevin Campbell AM, Chair, Telethon Institute for Child Health Research.

Harvey Coates AO, Senior ear, nose and throat surgeon, Princess Margaret Hospital for Children; Clinical Associate Professor, 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. (from Feb '07) Keith Jones, Board member, Deloitte Corporate Finance Pty Ltd; Managing Partner, Deloitte Touche Tohmatsu Western Australia.

Jenni Ker, President, Friends of the Institute.

Louis Landau AO, Professor, School of Paediatrics and Child Health, University of Western Australia.

John Langoulant, Chief Executive, Chamber of Commerce and Industry of Western Australia; Member, Senate of University of Western Australia. Graham Mitchell AO, Principal, Foursight Associates Pty Ltd.

Fiona Stanley AC, Director, Telethon Institute for Child Health Research; Executive Director, Australian Research Alliance for Children and Youth; Professor, School of Paediatrics and Child Health, University of Western Australia; Member, Prime Minister's Science, Engineering and Innovation Council; Australian of the Year 2003.

### Director's Report



Notching up research achievements is always something we celebrate. But to see those achievements translated into policies and actions that will improve outcomes for children and their families is where we, and the community, glean the real rewards. However as straightforward as that sounds, the leap from research into action is a much bigger challenge than most would anticipate.

Take the issue of folate as an example. It's been nearly 14 years since Institute Professor Carol Bower with myself and other international colleagues showed that folate intake before pregnancy could reduce the incidence of serious neural tube defects such as spina bifida by up to 70 per cent. What a breakthrough -- all we needed to do was ensure that women took folate before falling pregnant!

Easier said than done. In reality, only about half of all pregnancies are planned, and the folate message was not getting through to all women, particularly disadvantaged groups. So instead of a 70 per cent reduction, the rates reduced by about 30 per cent -- very disappointing for us, and devastating for families and children born with a birth defect that might have been prevented.

More than 40 other countries around the world decided to fortify their flour with the vitamin. Yet when we advocated for the same public health initiative here, we met an unexpected barrage of misinformation and scare campaigns from the flour and grocery industry -- despite the costs of fortification being less than one cent on a loaf of bread. In the past year we have expended much time and energy battling the huge public relations capacity of the food manufacturers. I'm very pleased to report that, after some delays and reviews, it appears that the regulatory authority, Food Standards Australia and New Zealand, has recommended mandatory fortification, and the Food Ministers around Australia have committed in principle to this important initiative.

This Institute is firmly committed to following through on its research findings to ensure that they result in real improvements in the health and wellbeing of children and families. It's something that we've done in terms of childhood vaccination, particularly to have the Hib Meningitis vaccine included on the immunisation schedule. It's also why we have committed significant effort to a communication strategy around the results of the groundbreaking Western Australian Aboriginal Child Health Survey, so that communities and governments can take this information and use it. It's why we engage with the media and also why we have made a commitment to significantly boosting consumer participation in all our research.

We cannot sit in a research ivory tower satisfied only by the quality of our science. It's imperative that we actively disseminate the information, and advocate for its use in informing policy development and programs. And many other institutes are realising that the communication of science and of research results is now an important part of our role.

It is this commitment to 'translation' that drew particular praise from the International Scientific Review Panel, that examined key aspects of the Institute's operations in November 2006. In their final report they commented that:

"... TICHR has developed into an exceptional model for integrating rigorous science, community engagement, and translation into policy and action of findings that have a public health and clinical impact. Although the TICHR is focused on child health, primarily in Australia, the model has very broad implications, and the strategies used by TICHR are worthy of global dissemination and adaptation."

Advocacy is certainly an important part of my role as Director, particularly through my role with the Prime Minister's Science, Engineering and Innovation Council, Executive Director of the Australian Research Alliance for Children and Youth and as an Ambassador for UNICEF.

This past year has resulted in more international recognition for the excellence of our work. I am very pleased to report that our Institute has been designated a World Health Organization Collaborating Centre for Research on Children's Environmental Health. The team is led by our head of Clinical Sciences, Professor Peter Sly, and is sure to add new knowledge to this area of growing public concern. I am pleased that this Centre has a commitment to environmental child health in developing countries. My belief is that those of us in the rich countries should help build sustainable capacity in those less well off -we can help to address the United Nations Millennium Development Goals by working with research groups in these areas.

The Institute's research leaders continue to attract very significant support from national and international competitive grants agencies. For example, National Health & Medical Research Council grants commencing in 2006 included renewal of a major Program Grant to Professors Sly, Holt and Thomas and external colleagues, a NHMRC Principal Research Fellowship to Associate Professor Prue Hart, a Career Development Award to Anita van den Biggelaar and several Project Grants. Dr Wendy Oddy had her work selected by the NHMRC for presentation as one of the 'Ten of the Best' projects for 2006, launched by the Federal Minister for Health.

Funding of our UWA Centre for Child Health Research as a State Government 'Centre of Excellence' commenced, allowing the purchase of a high speed cell sorter and expansion of our bioinformatics capacity. We continued our major contribution to another Centre of Excellence – Data Linkage Australia – and were a part of the research collaboration that attracted \$4.5million in seed funding to the Centre for Food and Genomic Medicine, to be based at the Western Australian Institute for Medical Research on the Sir Charles Gairdner Hospital campus.

Planning has begun for the potential relocation of the Institute to the QEII Medical Centre site, along with other key research institutes in WA and possibly the children's hospital.

The commitment to co-location is driven by the opportunities for collaborative research and its translation into the delivery of clinical best practice. Outstanding examples exist in the oncology, respiratory and allergy disease programs of the Institute and their counterparts in clinical service. Development of further opportunities will be enhanced by continued close proximity.

With the major reforms to Western Australia's health system, this State is in an unprecedented position to integrate research results directly into clinical practice and evaluate its results. In essence, that's what our Institute is all about -- excellent research that is translated into policy and programs to ensure better outcomes for children, and then a thorough evaluation of its effectiveness. It offers timeliness and accountability, and would be far cheaper than wasted expenditure on programs that aren't based on evidence and aren't evaluated for their impact.

I'd like to take this opportunity to congratulate our Board, staff, students and supporters on the outstanding results from the International Scientific Review. It validates our approach and confirms our position as a leading centre for child health research.

#### Fiona Stanley AC

## Our research aims to benefit every child.





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.ichr.uwa.edu.au** 

## Aboriginal child health

Throughout this report, the term 'Aboriginal' is intended to include people from Aboriginal and Torres Strait Islander backgrounds.

	About	Facts and stats
WA Aboriginal Child Health Survey	A survey of Aboriginal children from birth to 17 years that provides a comprehensive epidemiological "snapshot" of the health, development and wellbeing of Aboriginal children in their families, their schools and their communities. The survey also identifies the factors which promote resilience in Aboriginal children, exploring both individual and environmental aspects of childhood development. The survey was designed to build a store of knowledge from which preventive strategies can be developed to promote and maintain the healthy development and the social, emotional, academic, and vocational wellbeing of Aboriginal children.	It is the most comprehensive survey of Aboriginal children ever undertaken. It took five years of planning, two years in the field. Information was collected on more than 5,200 Aboriginal children in Western Australia, from metropolitan Perth to the most remote communities in the State. This is about one in every six Aboriginal children and young people living in WA. Interviews were conducted with 2,000 families and details were also gathered from teachers and principals. We worked in close collaboration with Aboriginal communities and agencies.
Rio Tinto Child Health Partnership	<ul> <li>Developed to deliver improvements in Aboriginal and Torres Strait Islander child and maternal health. Aims to achieve this through the delivery of three projects:</li> <li>modelling the WA Aboriginal Child Health Survey for the NT and QLD</li> <li>national fetal alcohol syndrome prevention strategy</li> <li>enhancing Aboriginal workforce capacity.</li> </ul>	<ul> <li>Partners include:</li> <li>Rio Tinto</li> <li>Alcohol Education and Rehabilitation Foundation Limited</li> <li>Western Australian government</li> <li>Northern Territory government</li> <li>Queensland government</li> </ul>
Otitis media	Otitis media (middle ear infection) can seriously affect childhood development, school performance and subsequent social and economic wellbeing.	Our Kalgoorlie Otitis Media Research Project was established in 1999 to investigate the causal pathways to otitis media and to identify demographic, socio-economic, environmental, microbiological and immunological risk factors for the disease in Aboriginal and non-Aboriginal children in order to develop appropriate interventions.

### **SPOTLIGHT ON** WA Aboriginal Child Health Survey

The United Nations Index of Human Development reflects aspects such as life expectancy, literacy and standard of living. Aboriginal Australians were ranked at 103 compared with Australia's overall population which is ranked number four.

Professor Steve Zubrick, Chief Investigator of the WA Aboriginal Child Health Survey, says this is unacceptable.

"Indigenous people in Canada, the US and New Zealand are all faring better than our Aboriginal people – that tells us we can and must take urgent action," he said.

The fourth volume of results from the Survey focuses on Aboriginal families and communities and throws new light on why most existing intervention programs are failing to produce results needed for overcoming the present levels of Indigenous disadvantage.

"What these results clearly show is the successive failure of programs that are

simply delivered too little, too late," Professor Zubrick said.

"What are desperately needed are high quality, high frequency early intervention programs that directly increase the capacity of Aboriginal parents and others caring for children – teaching them how to prepare their very young children so that when they start at school, they are ready and able to match it with others."

Professor Zubrick said that only an intense focus in the early years could

#### Our research

With a focus on educational outcomes for Aboriginal children, Volume Three was released in March 2006 and found that:

- Aboriginal students are starting well behind non-Aboriginal children and the gap widens the longer they are at school.
- 58 per cent of Aboriginal children were rated by their teachers as having low academic performance compared with 19 per cent of non-Aboriginal children.
- Only a quarter of Aboriginal students entering Year 8 go on to Year 12. Of those who start Year 11 just 22 per cent complete their Year 12 certificate, compared with 62 per cent of all students.
- Three major factors driving the poor outcomes for Aboriginal students are higher rates of school absenteeism, much higher prevalence of emotional and behavioural difficulties and parents and carers having generally lower levels of education.

Launched in November 2006, Volume Four of the Survey looked at strengthening the capacity of Aboriginal children, families and communities with key findings including:

- 24 per cent of Aboriginal children having significant emotional and behavioural needs
- I 6 per cent are living in poor quality housing
- 60 per cent are below average academically by Year I
- 28 per cent have teenaged mums, 31 per cent are in sole parent families and 20 per cent of teens are not living with either parent
- there is four times the levels of extreme stress.

#### Copies of all four Volumes released to date are available at <u>www.ichr.uwa.edu.au/waachs</u>

During 2006, a number of sites across Western Australia, Queensland and the Northern Territory carried out partnership activities including: developing ways to enhance and increase the Aboriginal and Torres Strait islander workforce in child and maternal health; the provision of culturally appropriate antenatal care and engagement of women at an early stage of their pregnancy; and delivery of services that reflect a holistic approach to the mother, baby and family that is culturally appropriate and in accordance with best practice processes.

The Rio Tinto Child Health Partnership hosted its inaugural national symposium in May 2006 which focused on promoting healthy pregnancy in Indigenous communities – *Start Out Strong:* A *Healthy Beginning in Life.* More than 170 delegates representing a wide range of organisations and communities involved in promoting healthy pregnancies in Indigenous communities attended the symposium. Dr Caroline Tait from the Indigenous Peoples' Health Research Centre at the University of Saskatchewan in Canada delivered the keynote address. The outcomes and future directions that arose from the symposium's workshops established clear messages about how best to promote healthy pregnancies in Indigenous communities which have been used to inform a range of stakeholders and advocate for program and policy change.

We followed 100 Aboriginal and 180 non-Aboriginal children from birth to two years of age in the Kalgoorlie-Boulder region. The burden of otitis media remains very high in the area with a peak prevalence of 72 per cent in Aboriginal children aged five to nine months and 40 per cent in non-Aboriginal children aged 10 to 14 months. Furthermore, 29 per cent of Aboriginal children and five per cent of non-Aboriginal children have had a perforated ear drum at least once by age two years, and 65 per cent of Aboriginal children and 23 per cent of non-Aboriginal children have some degree of hearing loss at age 12 to 17 months. We have reported high rates of upper respiratory tract carriage of the three major otitis media germs, with higher rates in Aboriginal than non-Aboriginal children. Carriage also begins at a young age in Aboriginal children. We also found that exposure to environmental tobacco smoke is associated with increased risk of otitis media.

begin to break the inter-generational cycle of disadvantage.

"There are just 1800 Aboriginal babies born in WA each year – that makes targeted 'head-start' programs to help them onto a strong path for life, a very practical and viable investment."

The volume makes 23 recommendations to address a broad range of issues including housing, financial strain, stress and how to boost capability within the Aboriginal community.



Kulunga Research Network Patron Troy Cook from the Fremantle Football Club with Isaiha and Sheliah at the Volume Four launch.

## Asthma, allergy and respiratory disease

	About	Facts and stats
Asthma	Asthma is characterised by episodes of cough, wheeze and breathlessness. These symptoms are caused by narrowing of the small airways in the lungs in response to triggers such as house dust mite, as well as inflammation and excess mucus production, which reduce airflow in and out of the lungs. We are recognised as a world leader in research for the prevention and treatment of asthma. We are focusing on how asthma develops, better ways to manage and monitor asthma and new treatments.	Asthma is the most common chronic illness in children. In Australia, asthma affects around 40 per cent of children and adolescents. There is no current way of preventing the development of asthma - all treatments are designed to control asthma symptoms once they have developed. The western world has seen a dramatic increase in the prevalence of asthma in the past few decades, and while there is no doubt that factors associated with the "western way of life" are involved, the precise cause of the increase remains elusive. As well as environmental and physical factors, psychosocial factors may play a part.
Cystic fibrosis	Cystic fibrosis (CF) is a genetic disease that affects a number of organs in the body (especially the lungs and pancreas) by clogging them with thick, sticky mucus. In the lungs, this mucus clogs the tiny passages in the lungs and traps bacteria. Repeated infections and blockages can cause irreversible lung damage and death. In the pancreas, mucus can prevent the release of enzymes needed for the digestion of food, resulting in people with CF having problems with nutrition.	Cystic fibrosis is the most common life threatening, recessive genetic condition affecting Australian children, with around one in every 25 people carrying the CF gene. Around one in every 2,000 babies born in Western Australia will have cystic fibrosis. There is no known cure.
Allergy	People can become allergic to natural, harmless substances in the diet or inhaled air. If this occurs they will develop harmful inflammatory responses to subsequent exposure. The symptoms of food allergy can be itching, swelling, nausea and diarrhoea, and for allergy to inhaled substances they can be asthma attacks and the symptoms of hay fever. Serious allergies can cause anaphylactic shock, which is a sudden aggressive and potentially life-threatening reaction.	Allergies to food and inhaled substances have more than doubled over the last few decades. About six per cent of children develop food allergy and 30 per cent develop respiratory allergy. The most common inhalant allergies are to house dust mites, grass pollen and cats. The common food allergies are to milk, egg, soy, peanuts and tree nuts. Many children grow out of the milk and egg allergies in infancy while allergy to nuts tends to persist especially for highly allergic children.

### **SPOTLIGHT ON** Asthma vaccine study

The Institute is leading a world-first research trial into a treatment that could prevent asthma in high-risk children.

The treatment, developed by the Institute's Professors Pat Holt and Peter Sly, involves exposing babies and toddlers to tiny doses of common allergens as an oral vaccine to stimulate immune responses which protect against allergy.

The children are being given daily drops

16

under the tongue of house dust mite, grass and cat allergen over a 12-month period and will then be monitored closely for three years.

"If we can prevent allergies in young children, we should be able to prevent them going on to develop asthma that is triggered by the allergies," Professor Holt said.

"We expect that the drops will act, in effect, as an asthma vaccine – educating

the immune system to avoid harmful responses to these allergens.

"However, it's important to understand that this vaccine would never be a one-off dose, but a sustained course of treatment over months to gradually modify the immune reaction."

The research team said the problem with traditional approaches is that they start too late – after a child has already developed an allergy.

#### **Our research**

We are very excited to be leading a world-first international trial of an asthma vaccine for children at high risk of developing asthma. The trial involves giving children drops under the tongue of a mixture of the three most important allergens known to be associated with asthma in the trial sites of Australia, USA, Sweden and Germany - these are house dust mite, cat and grass allergens. The aim of the vaccine is to educate the immune system to develop immune responses which protect against allergic sensitisation. Two hundred high-risk children aged between 18 and 30 months will have the drops every day for 12 months and will then be followed for a further three years to see if the effect is long-lasting.

We are developing a world first system for predicting the severity of asthma in young children. The system is being developed through analysis of asthma data from thousands of West Australian children which have been collected as part of ground breaking studies at the Institute. The system is the culmination of many years work unlocking the risk factors that lead to some children developing chronic disease, while others outgrow asthma. A collaboration agreement has been signed by Institute spin-off company Advanced Diagnostic Systems with a major European diagnostic development company and prototypes of the new system are planned to be developed over the next two to three years.

Our research into the links between asthma and sunlight have shown that exposure to ultraviolet light for 15 to 30 minutes before allergen exposure significantly reduces the development of asthma-like symptoms in mice. This UV exposure produces a cell type that, when transferred into other mice before they're sensitised to an allergen, can prevent the development of some of the asthma-like symptoms. It appears that sunlight can suppress specific immune reactions, so the research team are now working to better understand that mechanism with the aim of generating new ways to prevent and treat this chronic disease. Given that overexposure to sunlight can cause skin cancer, it is important that the beneficial elements of ultraviolet light are isolated and separated out, in order to develop a safe and effective asthma therapy.

Our research focuses on the early development of lung disease in children with cystic fibrosis. We have collected more than 400 lung fluid samples from 100 children with cystic fibrosis to determine the level of inflammation in the lungs. The role of inflammation is to attack invading disease-causing organisms and to effectively remove them from the body. For children with cystic fibrosis, inflammation overwhelms the lungs and causes excessive levels of enzymes which can also attack lung tissue, leading to long-term irreversible lung damage and pulmonary function decline. We have developed a urine test that measures the destruction of lung tissue. Children with cystic fibrosis and children with no history of lung disease have been recruited and we have been testing their urine samples for evidence of the proteins that occur following lung damage. We want to see if these protein levels correlate with inflammation levels at times of good and bad health for children with cystic fibrosis. We are also investigating whether anti-inflammatory therapies currently being trialled nationally and internationally in people with the disease, will help reduce levels of lung damage. We combine these research results with clinical information on lung function and CT scans to predict the onset of early lung disease in order to develop preventative strategies.

Our research into cat allergens, the second most important indoor allergen that causes asthma, has shown exciting results. We have identified a new cat allergen which is important for the development of new therapies for those who are cat allergic. It is recommended that allergy sufferers avoid contact with cats. However, this is difficult because cat allergens stick to walls, furniture and small dust particles. These particles can be easily transferred from homes into the community by cat owners on their clothes and hair and high amounts of the major cat allergen called *Fel d 1* have been found in public places, schools and work places and can accumulate over a short period of time. These amounts can be enough to induce sensitisation. To date, research has been focused on *Fel d 1* as it is the strongest binding and most easily isolated protein. However, research has suggested there are at least 10 important cat allergens and our research has identified a new allergen called *cat BASE*, which was isolated from cat saliva. In our study group of cat allergic people, more than 50 per cent reacted to *cat BASE* suggesting it is important in sensitisation. Further research will look at identifying more cat allergens.

We are also continuing our studies into house dust mite, the most important indoor allergen in our region.

"We already know that children with a family history of allergies or asthma are at a much higher risk of developing serious asthma that will persist into adulthood," Professor Sly said.

"The innovative aspect to this approach is that we will be targeting these children very early in life and teaching their immune system to ignore these allergens – well before they've even developed an allergic reaction, let alone asthma," he added.



Two-year-old Benjamin is one of the first children in the world to participate in the asthma trial.

### Cancer

	About	Facts and stats
Leukaemia	Leukaemia is cancer of the white blood cells. These white blood cells are produced in the bone marrow. In leukaemia, these white cells undergo a malignant change or become cancerous. They divide uncontrollably and interfere with the ability of the bone marrow to produce normal blood cells. Large numbers of cancerous cells are released from the bone marrow into the bloodstream and travel around the body.	<ul> <li>Leukaemia is the most common form of cancer in children, accounting for around one third of all cases.</li> <li>Leukaemia affects around one in every 2,000 children in Australia.</li> <li>It is more common in boys than girls with a 1.4 to 1 ratio.</li> <li>There is a peak incidence in children aged between two and four years.</li> <li>Survival rates have increased to more than 70 per cent.</li> <li>Our leukaemia research Division is a member of the US-based Children's Oncology Group, the world's largest study group into childhood cancers.</li> </ul>
Brain tumours	We are interested in primitive neuroectodermal tumours (PNETs), the most common type of brain tumour affecting children.	Brain tumours are the second most common form of cancer in children. Survival rates are between 50 and 70 per cent.
Skin cancer	Skin cancer is predominantly caused by overexposure to the sun's ultraviolet radiation. We are interested in basal cell carcinoma, the most common type of skin cancer, which is one type of non- melanoma skin cancer. Our research also focuses on melanoma.	Australia has the highest rate of skin cancer in the world with one in two people who spend their life in Australia developing some form of skin cancer. Melanoma is the most serious of all skin cancers but is less common, accounting for around five per cent of all skin cancer cases.

### **SPOTLIGHT ON** Australian Study of Causes of ALL in Children (AUS-ALL)

Acute lymphoblastic leukaemia or ALL is the most common cause of cancer in children. We are comparing information provided by the families of children with ALL to information from children who do not have the disease to help researchers gain an insight into factors that may be related to this type of leukaemia.

Chief Investigator Dr Liz Milne says a very important part of the study is to look at environmental factors that may affect the risk of disease. "One of the main areas we are looking at is the parents' occupational histories," she said.

Translating the information collected from parents into a 'measure of exposure' is a complicated process.

"We are interested in parents' occupational exposure to substances such as pesticides, engine exhaust, solvents and paints," Dr Milne said.

"We particularly want to know about

jobs parents had before the child was conceived and during the pregnancy."

"So both parents fill out a questionnaire about their jobs and the main tasks performed every year from when they started work until their child's birth. If this information suggests the parent may have been exposed to one of the substances of interest, then detailed information is collected by phone.

"For example, a farmer will be asked about the types of herbicides he used

#### **Our research**

Despite the high cure rates, resistant forms of childhood acute lymphoblastic leukaemia (ALL) are still a significant cause of cancer-related death and disease in children. Survival rates for children with leukaemia have reached up to 85 per cent for patients of standard risk and 64 to 75 per cent for high-risk patients. However, a substantial number of standard risk patients continue to relapse. We are studying cell lines of patients who have relapsed to increase our understanding of the mechanisms involved in therapy failure and the drug resistance of some forms of childhood leukaemia.

We are interested in the genetic events leading to leukaemia in children and applying this knowledge to develop improved prognostic assessments for patients. We use our panel of established cancer cell lines and novel microarray technology (which allows us to look at more than 20,000 genes at the same time) to look at the genetic differences between cancer cells and normal cells, and to test anti-cancer drugs.

In 2006, we continued our population-based research into the possible genetic, environmental and dietary causes of ALL. Australian children are providing important information that will help us understand why certain children get leukaemia and how it may be prevented. We have been recruiting children newly-diagnosed with ALL between 2003 and 2006 and matching them by age, gender and State of residence to children without leukaemia. Children who have achieved remission from ALL have been recruited through paediatric oncology centres around Australia, and to date, 379 families have consented to take part in the study. Of these, we have collected DNA from 363 children, and 323 families have completed questionnaires. 658 families of children without leukaemia have completed food questionnaires and 495 have provided DNA samples. In total, occupational exposures have been assessed in around 800 families.

PNETs are an aggressive type of tumour with five-year survival rates remaining in the 50 to 70 per cent range. A significant proportion of patients do not survive and many of those who do, face serious post-treatment quality of life issues, as a result of brain surgery and chemotherapy or radiotherapy. Our laboratory is focusing on the molecular biology of PNETs as there has been little previous research in this area and the complex features of brain tumours are only partly understood. If we can gain a better understanding of the disease we can work towards developing safer and more effective drugs and treatments for PNET patients. We are also looking at the relationship between neural stem cells and brain cancer stem cells in the hope of identifying deregulated genes linked to tumour development.

2006 saw the completion of the first year of a new study looking at the effects of genetic and environmental factors on the risk of childhood brain tumours. Families with a child with a brain tumour were recruited and we began collecting important information about diet, environmental exposures and occupational history as well as DNA samples. Control children will be matched to each child who had a brain tumour, with further recruitment of both groups of children occurring during 2007.

The ultraviolet rays in sunlight not only cause sunburn, they can also suppress the immune system as well as turn a normal skin cell into a cancerous one. The effect on the immune system can result in a developing skin cancer avoiding destruction by an active immune response. Interestingly, these UV rays can penetrate only a few millimetres into the skin, yet their effects on the immune system are widespread in the body. We have identified some of the critical early events initiated in the outermost layer of skin which affect immunity. Currently we are identifying the changes that are made to cells of the immune system initiated by those early events. Our research has shown that these changes in immunity are important for melanoma and basal cell carcinoma, and probably all skin cancers.

An important consequence of UV radiation of skin is the production of vitamin D, which is not only important for bone growth, but it can also affect the immune system and may also affect cancer growth. Our current research is looking at the contribution vitamin D makes to the immune system changes following exposure to UV rays. If the vitamin D made in response to sunlight makes it a "good thing", we're mindful that in this instance you can easily have "too much of a good thing" and our research is therefore looking for ways of getting, from sunlight, the benefits without the risks.

and what type of protective clothing was worn at the time."

All of the information is then sent to an expert occupation hygienist who estimates the level of exposure for each job. Finally, the exposures from every job a person has had are added together to come up with a measure of the likely extent of exposure.

Researchers will use all the information collected from families, including occupational histories, to help in their understanding of factors that may be related to ALL in children.



The AUS-ALL study team Dr Liz Milne, Somer Dawson and Helen Bailey

## Healthy development

	About	Facts and stats
Western Australian Pregnancy Cohort (Raine) Study	The Raine Study began in the late 1980's to examine how events during pregnancy and around birth influenced the subsequent health of children. Almost 3,000 women were enrolled at between 16 and 20 weeks in pregnancy and their children have been followed at birth, one, two, three, five, eight, ten, 13 and now 16 years of age.	The study is one of the most extensive surveys of pregnancy and early childhood to be carried out anywhere in the world. The Raine Study represents a collaboration between the Institute, the Women and Infants Research Foundation at King Edward Memorial Hospital, The University of Western Australia Department of Paediatrics at Princess Margaret Hospital, Curtin University of Technology and the University of Notre Dame.
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. It is also associated with psychosocial problems such as low self-esteem, depression and problems with peer relations.	Australia-wide data suggests that 19 to 23 per cent of Australian school children are either overweight or obese. Obesity rates have trebled in children and young adults in Australia over the last 20 years.
Speech and language development	Specific Language Impairment (SLI) is a disorder where a child has markedly delayed language development but with no other developmental delay or disorder apparent. These children do not have a hearing or intellectual problem, but have a specific problem in understanding and expressing themselves.	SLI currently affects approximately seven per cent of single-born children with otherwise normal development. This equates to around 7000 West Australian children in Kindergarten to Year Two with SLI. The rate of SLI in twins is not known.
Developmental pathways in WA children	This project is looking at developmental pathways to health, education and delinquency outcomes in Western Australian children. The project will use a holistic approach to inform early intervention strategies to enhance wellbeing and life chances.	This project will be the first time that a State-wide, whole of population study involving a number of industry partners and government departments has been undertaken in Australia.

### **SPOTLIGHT ON** The Raine Study

A new phase of the Raine Study commenced in June 2006.

With the study teenagers now 16 years of age, researchers have a unique opportunity to look at the development of physical characteristics and other factors that can determine the life-long health status of individuals.

As part of the 16-year assessment, the Raine Study team will be using a SphygmoCor machine to measure the flexibility of the study teenager's blood vessels and the velocity at which the blood moves through their blood vessels.

During this test, the teenager has a three-lead ECG fitted and recordings of their pulse are analysed at the neck and the top of the foot (to determine blood velocity) and the wrist (to determine blood vessel elasticity).

These measures provide important information on cardiovascular health

in teenagers, particularly signs of heart disease and hardening of the arteries and high blood pressure.

High blood pressure is already a leading cause of cardiovascular health problems globally which will be further exacerbated by the increasing rates of obesity and diabetes.

We would like to better understand the development of overweight, obesity and high blood pressure with a view

#### **Our research**

In May 2006, the last of more than 1600 assessments in the 13-year follow-up was completed. This phase of the Study collected information about patterns of behaviour that develop from a very early age, and circumstances that are related to levels of physical activity and the consequences of inactivity such as obesity, elevated blood pressure, diabetes, low back pain and 'high risk' behaviour.

The Raine Study 16-year follow-up began in June 2006 and is building upon information collected in previous follow-ups. The research will concentrate on cardiovascular health, the prevention of back and neck pain, good nutrition and mental health, the prevention of diseases of the liver and the pathways by which genes affect health and development. We will be looking at the link between high blood pressure and cardiovascular health; the physical, lifestyle and psychological factors thought to contribute to the development of back and neck pain in childhood and adolescence; the role of childhood nutrition in the development of mental health problems; ways to prevent and successfully treat diseases of the liver such as non-alcoholic fatty liver disease, coeliac disease and haemochromatosis; and learning more about some of the complex pathways by which genes affect the functioning of the central nervous system and the endocrine system which produces hormones, such as cortisol.

Our research aims to identify the various biopsychosocial factors that contribute to the development and persistence of childhood obesity, to allow us to develop appropriate prevention and intervention strategies for specific groups of children.

During 2006, we continued to assess and recruit children from metropolitan Perth. We have conducted initial interviews with 483 children and their parents. Over 320 children have completed their one-year assessment, 190 children have completed their two-year assessment and over 50 children have finished their three-year follow-up.

Three groups of primary school-aged children are involved in our research – a community sample of overweight/obese children, a community sample of healthy weight children, and a sample of obese children currently seeking treatment for obesity-related conditions. We are collecting height and weight data as well as information on biological, psychological and social/environmental factors that are suggested to influence the persistence of childhood obesity into adolescence and adulthood.

Our LOOKING at Language study aims to understand more about genetic and environmental factors that influence language acquisition and Specific Language Impairment in twins and single-born children aged between two and six years.

Children with SLI face many challenges at school, with half behind in their reading and a third with social or emotional difficulties. Our five-year study is addressing two of the four USA National Institutes of Health priority areas for research in communication disorders - determining factors that contribute to or cause normal and disordered communication, and developing and refining diagnostic criteria to facilitate early diagnosis of communication disorders. Knowledge about pathways to language, learning and social and emotional disorders in toddler, preschool and school-aged children will inform health and education policies on how to provide services that promote good developmental outcomes for children with language difficulties.

This research project aims to identify causal pathways and early determinants of human developmental outcomes. A better understanding of these outcomes and their interconnections is essential for early, cost effective and holistic interventions. Health, wellbeing and competence among our children and youth are critical human resources upon which future economic prosperity will depend.

In the second year of the project, we have continued to work closely with the University of Western Australia (Crime Research Centre) and the industry partners - Department of Health, Department of Education and Training, Department of Community Development, Department of Corrective Services, Disability Services Commission, and the Office for Children and Youth. Working with the WA Data Linkage Unit, we have begun the process of linking de-identified data from the industry partners to address questions in the five research themes: education, socioeconomic inequalities, Aboriginal, juvenile delinquency, and child protection.

to identifying the relative importance of influences both before and after birth.

These and other information collected by the Study are vital in helping researchers better understand and develop more effective ways to prevent and/or successfully treat conditions such as overweight and obesity, back and neck pain, depression, and non-alcoholic fatty liver disease.



Research assistant Diane Wood takes a wrist pulse reading from Brooke using the SphygmoCor machine.

## Infectious disease

	About	Facts and stats
Meningitis	Meningitis is the inflammation of the meninges (the membrane lining of the brain and spinal cord). It usually refers to infections caused by viruses, bacteria, fungi or other micro-organisms such as parasites. Bacterial meningitis is the most common life- threatening type of meningitis and can cause death within hours. Most cases of bacterial meningitis in children and adults are caused by meningococcal and pneumococcal bacteria.	In Australia, meningococcal B and C strains cause the most disease. In WA, over 80 per cent of meningitis cases are caused by the B strain. The introduction of Commonwealth Government- funded vaccines for Hib, pneumococcal and meningococcal C meningitis has seen case numbers drop significantly.
Pneumococcal disease	Invasive pneumococcal disease caused by the bacteria called pneumococcus ( <i>Streptococcus pneumoniae</i> ) is a major cause of meningitis, pneumonia (inflammation in the lungs), septicaemia (blood poisoning) and severe ear infections. The pneumococcus is often carried in the back of the nose and throat and upper respiratory tract of healthy children and adults. Many people naturally carry the bacteria in the back of their nose but few become ill.	Throughout the world an estimated one million children die annually from pneumococcal disease, the majority being in early infancy. In 2006, there were 131 reported cases of invasive pneumococcal disease and 10 deaths in WA.
Influenza	Influenza, or the 'flu is caused by a highly contagious virus spread by coughing and sneezing. Symptoms of the 'flu develop one to three days after infection and include chills, sweating, headache, cough and general muscle and joint pains. In rare cases, 'flu may lead to serious complications such as pneumonia or inflammation of the brain or heart.	The 'flu is often considered a mild disease, slightly worse than a cold, but the 'flu has killed millions of people, including children, around the world. Children are two to three times more likely than adults to get sick with the 'flu and be hospitalised.
Human Papillomavirus (HPV)	HPV is a virus that infects the skin and mucus membranes of the human body. Most people who become infected with HPV will not have any symptoms and will clear the infection on their own. There are more than 100 different types of HPV.	HPV is the main cause of cervical cancer in women, with approximately 70 per cent of all cervical cancers being associated with infection with only two types, HPV 16 and HPV 18. Over 75 per cent of sexually-active women and men will be infected with HPV during their lives.

### **SPOTLIGHT ON** Bird flu vaccines

Avian influenza or bird 'flu is an infectious disease of animals (usually birds) caused by some strains of the influenza A virus.

Human infection with these influenza A types is rare but in 2003, the largest and most severe bird 'flu outbreak in history began in South East Asia, caused by the H5N1 strain of the virus.

Perth adults, children and seniors have been helping the fight against bird 'flu by taking part in trials of a new, Australiandeveloped vaccine to protect against the potentially-deadly disease.

And the study has shown promising results, with the first trial in adults showing the majority of study participants produced a neutralising antibody response against the H5N1 bird 'flu virus.

Perth study leader Dr Peter Richmond said the vaccine was found to be safe and well tolerated and the data has now been submitted for registration of the vaccine with the Therapeutics Goods Administration.

"We've always said that the best preparation against bird 'flu is to have a vaccine available, so we are very pleased to have been part of this important trial," Dr Richmond said.

"The volunteers have played a really critical role in helping to have a vaccine available to protect Australians in the event of an influenza pandemic."

#### **Our research**

During 2006, we were part of an exciting world-first trial of a new meningococcal B vaccine. Group B disease is the last main cause of meningitis in children for which there isn't an effective vaccine. The vaccine was found to be safe and to stimulate protective antibodies in adults and is now being studied in toddlers and adolescents eight to 14 years of age, as these groups are at high-risk for meningococcal B disease. Other studies included trials of new combination vaccines against meningitis which hope to reduce the number of injections children need.

The Meningitis Centre, which is housed at the Institute, is Australia's premier organisation for information about meningitis. The Centre has been working with the community and government since 1992 to raise awareness of all forms of meningitis and funding for vaccines. The Centre also provides support and information to families affected by meningitis and works to increase public awareness of, and foster research into, meningitis.

Bruce Langoulant, Chairman of The Meningitis Centre, is also President of the international Confederation of Meningitis Organisations (COMO). COMO is an organisation of medical and charity leaders from across the world united to increase the international profile of meningitis. More information about The Meningitis Centre may be found at <u>www.meningitis.com.au</u>

We continue to monitor cases of invasive pneumococcal disease through the Vaccine Impact Surveillance Network, which collects and analyses information on vaccine-preventable diseases and evaluates the impact of vaccines. From April 1 1996 to December 31 2006, a total of 1790 cases of invasive pneumococcal disease were recorded on the database. With the introduction of universal infant pneumococcal vaccination in 2005, the number of cases in children under five years of age fell from 47 in 2004 to 18 in 2006. Continued monitoring is important to ensure early detection of non-vaccine strains of the pneumococcus causing disease.

We are also working with the Papua New Guinea Institute of Medical Research to immunise young infants in Papua New Guinea with pneumococcal conjugate vaccine. The vaccine is being given to babies either at birth and/or one and two months of age to see if immunisation in early life will protect them against pneumococci which causes acute respiratory infections and meningitis that can result in death. Recruitment for the study continued during 2006 and by the end of the year, 233 babies were enrolled.

Influenza vaccine is being increasingly recommended for young children, so we have been looking at how well an Australian 'flu vaccine works in young children. We have now followed up children for a second year and have found that the 'flu vaccine was safe and produced protective antibodies even in young children. They also responded well to a booster dose 12 months later. The findings from this study have led to changes in recommendations for the best dose of this vaccine to be used in young children.

During 2006, the Vaccine Trials Group at the Institute tested an Australian-developed bird 'flu vaccine in 200 Perth adults (with a further 200 involved in Melbourne and Adelaide) with results showing the vaccine was well tolerated and that both dose levels (two or three times the normal 'flu vaccine) produced antibody responses that neutralised the virus in the majority of adults. This data has been used to register the vaccine with the Therapeutic Goods Administration for use in the event of a pandemic. Studies are continuing through 2007 in older Australians and children aged between six months to eight years.

We have been involved in several studies of new HPV vaccines that have now both been licensed for use in Australia. Previous studies of the Australian-developed Gardasil<sup>™</sup> vaccine were successful in teenage girls and young women and this vaccine is now being recommended for all adolescent girls and women up to 26 years of age. We continued studies of another HPV vaccine, Cervarix<sup>™</sup>, which was found to be safe and well tolerated in girls and prevented HPV infection and pre-cancerous changes in young women. Trials have now been expanded to include older women to see if the vaccine is beneficial in women who may have already been exposed to the HPV virus.

Trials in children and older Australians are continuing into 2007.

"In any 'flu pandemic, young children and older people are particularly at risk for serious complications of the disease," Dr Richmond said.

"Children also play an important role in the spread of influenza viruses in the community."

With no live virus in the vaccine, there is no chance of catching the infection from the vaccination.



Study nurse Shalene Nandlall vaccinates Olga against bird 'flu. They are watched by Olga's son Geoff, his niece Sarah and daughter Emily who are also part of the trial.

## Social and emotional wellbeing

	About	Facts and stats
Dietary patterns and mental health	Several independent lines of research have converged in showing that deficits in omega-3 fatty acids are associated with neuro-endocrine functioning and susceptibility to affective disorders (depression) in adult populations. There have been major changes in the 'average' diet in western developed countries as a result of the industrialisation of food production and increased consumption of highly-processed foods. Despite these changes there has, until recently, been surprisingly little research into the role which dietary quality plays in shaping children's brain development, their behaviour and emotions.	Child and adolescent mental health problems are common and burdensome problems affecting around one in six WA children in any one year. Depression has become more frequent in children and adolescents over recent decades. The average age of onset of these problems has also become progressively earlier over this period. One of the most striking aspects of the change in the 'average' western diet is a 20 to 30 fold increase in the ratio between omega-6 and the omega-3 fatty acids.
Proactive support for families bereaved through suicide	Family and others with significant attachments to individuals who commit suicide are at increased risk for pathological grief reactions which may include clinically significant depression and suicidal behaviour.	Around 250 Western Australian families are bereaved through suicide each year: For each suicide it is estimated that an average of six other individuals are directly affected by the often traumatic nature of such bereavements. Next of kin and other family have very particular support needs in dealing with the acute distress and the longer-term complicated bereavement recovery process.
Growing up in Australia: The Longitudinal Study of Australian Children	<ul> <li>10,000 children and their families have been recruited to the LSAC The study is following two representative groups of children recruited in 2003/04 - 5,000 children under 12 months of age and 5,000 aged four to five years.</li> <li>The study aims to provide the database for a comprehensive understanding of children's development in Australia's current social, economic and cultural environment, and to become a major evidence base for future policy and practices regarding children and families.</li> </ul>	LSAC is the largest and most ambitious study ever carried out on Australian children. The children in the study represent two per cent of all the children born in Australian in their year of birth.

### **SPOTLIGHT ON** Life at 1

Many people would recognise Professor Steve Zubrick, Head of the Institute's Division of Population Sciences, as one of the faces and voices of the Life at I documentary that screened on ABC TV.

Made in conjunction with the Longitudinal Study of Australian Children (LSAC), a long-term study of 10,000 Australian children, this groundbreaking documentary takes a look at what creates a happy, healthy child and what makes us who we are.

24

Professor Zubrick is Chair of the LSAC Consortium Advisory Group and says that never before have we been able to get a whole picture of an Australian child's life.

"What we hope to find out through this study is what every parent has always wanted to know - what does it take to give a child the best chance at life."

Life at I is the first instalment in a series following II babies and their families over time, looking at the impact on their lives of factors such as the relationship between parents, the family's financial position, the impact of work on family life and parent's health and education.

Life at I draws on many aspects of the LSAC. However, the families have been recruited separately from the main study and there are some differences.

"Families involved in LSAC are anonymous whereas in Life at 1, these families have let the cameras into their lives so we can see them grow and develop.

#### **Our research**

Our initial studies of dietary quality and mental health outcomes in the Raine Study children have shown that 23 per cent had externalising or internalising mental health problems some or all of the time between three and 15 years of age. These children were more likely to have a lower diet quality score as measured by our diet quality index. As their mean diet quality score increased, all domains of mental health improved, suggesting that healthy diets should be encouraged in adolescent children for the benefit of their mental health and wellbeing.

Funding from the Australian Rotary Health Research Fund in 2006 has enabled the continuation of this work looking at dietary factors and trajectories of mental health from infancy to adolescence. This is the largest and most comprehensive study of its kind investigating the link between patterns of mental health and nutrition through childhood and adolescence and the way in which this is related to other psychosocial and economic factors.

Our current studies are validating dietary intake measures (food frequency diaries) against blood assays of essential fatty acids and other key nutrients. These measures are then being used in conjunction with measures of children's psychosocial and economic environments of childrearing to quantify the potential benefit which nutritional interventions may offer to addressing the apparent increase of behavioural and emotional problems experienced by children and young people today.

The Ministerial Council for Suicide Prevention (MCSP) has previously undertaken consultation research with families bereaved through suicide. This identified that the availability of bereavement support interventions and more active interventions would have assisted them in being able to engage with appropriate supports at an earlier stage in the bereavement recovery process.

During 2006, the MCSP consulted with the WA Coronial Counselling Service, the WA Police Coronial Investigations Unit, the Samaritans and other grief counselling providers, mental health services and primary care providers (GPs) to initiate the development of an innovative outreach bereavement support model which could be trialled in the Perth southern metropolitan area. This resulted in a successful MCSP application for National Suicide Prevention Strategy funding of \$1.3 million to introduce and evaluate the new service from 2007 to 2009.

The Curtin University Centre for Developmental Health at the Institute is a consortium partner with the Australian Institute of Family Studies and nine other Australian research institutions who are conducting this landmark study. Professors Stephen Zubrick (Chair) and Sven Silburn are both members of the LSAC consortium advisory group which is overseeing the design and implementation of the study.

LSAC examines the impact of Australia's unique social and cultural environment on the next generation. The study explores family and social issues relevant to children's development, and examines a range of research questions about family functioning, health, non-parental child-care, and education. The longitudinal nature of the study will enable researchers to determine critical periods for the provision of services and welfare support, and to identify the long-term consequences of policy innovations. By tracking children over time, LSAC will be able to determine the individual, family, and broader social and environmental factors that are associated with children's developmental trajectories. The outcomes from the study will be able to be used to inform the development of effective social and family policy in Australia.

During 2006, Professor Zubrick led a research group which won a competitive government tender to analyse the LSAC wave one data to prepare a special monograph entitled "Parenting and families in Australia." Another report in child care in Australia is being prepared based on the LSAC data. Both of these publications are due to be launched by the Australian Government in mid 2007.

Also in 2006, the two-part documentary film called Life at 1 was released and screened nationally on the ABC. Professor Zubrick contributed to these documentaries as the Chair of the Consortium Advisory Group and provided scientific commentary throughout both films.

"As the LSAC progresses over the next few years, Life at 1 will continue to track the progress of these 11 babies."

Episode One of Life at 1 explores how childcare, IVF, large families, playgroups, racism and premature birth might shape the personality of a child. Episode Two looks at the ordinary and extraordinary stresses in a modern child's life such as attending a childcare centre, a family tragedy and illness.

Life at 3 is due for release in 2008.



The Longitudinal Study of Australian Children was the inspiration for Life at 1, a documentary which tracks the lives of 11 babies and their families.

## The early years

	About	Facts and stats
Australian Early Development Index (AEDI)	The AEDI project is enabling communities around the country to assess how their children are doing in terms of early development and readiness for school learning. A unique online data entry system allows teachers to complete checklists on five areas of child development: physical health and wellbeing; social competence; emotional maturity; language and cognitive skills; and communication and general knowledge. The AEDI project is a partnership between the Institute and the Centre for Community Child Health in Melbourne. It is funded by the Australian Government Department of Family, Community and Indigenous Services (FACSIA) and Shell Australia.	<ul> <li>Between 2004 and 2006 the AEDI was trialled in 54 Australian communities over six states and territories on more than 30,000 children.</li> <li>Each participating site ranges in geographical size and number of children, from single rural towns with small numbers of children to entire health services and local government regions.</li> <li>The AEDI is based on the Canadian Early Development Indicator (EDI) which was adapted and validated for use in Australia.</li> </ul>
The importance of breastfeeding	<ul> <li>According to the Australian Breastfeeding Association, breastfeeding:</li> <li>protects your baby from illness and infection</li> <li>provides the correct food for your growing baby</li> <li>aids the development of your baby's eyesight, speech and intelligence</li> <li>promotes a special loving bond between mother and baby.</li> </ul>	The World Health Organization recommends exclusive breastfeeding for six months, then introduction of complementary foods and continued breastfeeding thereafter. It is recommended that breastfeeding continue until 12 months of age and thereafter as long as mutually desired.
Childhood deaths	Our WA Mortality Database describes the deaths of every Western Australian-born infant, child and young person. It is important to understand why our children are dying so we can work towards improving programs and services aimed at reducing childhood death.	The database describes the cause, location and circumstances of death for all infants, children and young people born in WA between 1980 and 2002 inclusive.

### **SPOTLIGHT ON** Australian Early Development Index

The Australian Early Development Index (AEDI) is a tool for helping communities assess how well children are developing before they start school.

Between 2004 and 2006 the AEDI was completed on 9,894 West Australian Pre-Primary children in 22 communities.

This included Mirrabooka, a site of significant disadvantage where the community is characterised by high unemployment rates, low income levels and a very high proportion of single parents, non-English speaking recent migrants, refugees and Indigenous families.

The AEDI results for this area are the poorest found for any community across Australia.

The Federal Government's Stronger Families Stronger Communities initiative granted Communities for Children (C4C) funding to the Mirrabooka region.

The resultant local C4C Steering Committee utilised the AEDI results to develop a four-year strategic plan and implement five key projects specifically aimed at improving child development and thus future AEDI results.

Institute researcher Sally Brinkman said the foremost project was an Early Literacy Links Program which included a *Lets Read* component funded by Shell Australia.

"Let's Read, in conjunction with the local city council libraries, the State Library, local child health nurses and playgroup

#### **Our research**

Results for the three-year study period between 2004 and 2006 show that almost a quarter (23 per cent) of children surveyed were developmentally vulnerable on one or more domains of the AEDI, that is, the children scored below the AEDI cut-off. These children demonstrate a much lower than average ability in the skills measured in that domain. A smaller proportion of children (11 per cent) are considered to be developmentally vulnerable on two or more domains and therefore are at higher risk developmentally. However, it should also be noted that the majority (65 per cent) of all children surveyed were performing well on one or more domains of the AEDI. These are children who score in the top 25 per cent of the domain.

The AEDI process facilitates community partnerships across sectors, encouraging schools, local governments, businesses, community groups, service providers and families to work together to improve programs and services for children. The AEDI provides solid data for planning and evaluation and highlights variations in children's development within the geographic areas in the community so that services are best targeted to the areas that need them most.

Funding from FACSIA and Shell Australia from 2007 to 2009 will now enable the communities to re-run the AEDI and develop and trial an Indigenous AEDI.

Further information about the AEDI can be found at www.australianedi.org.au

There is growing scientific interest in the possibility that early nutrition is an environmental factor associated with the increase in mental health and behavioural problems which has occurred in most developed countries in the past 30 years. However, relatively few studies have considered nutritional factors in the development of child and adolescent mental health.

Our research has shown that babies that are breastfed for longer than six months have significantly better mental health in childhood, adding to the growing evidence that bioactive factors in breast milk played an important role in the rapid early brain development that occurs in the first year of life. The study found that children who were breastfed for less than six months compared with six months or longer had a 52 per cent increased risk of a mental health problem at two years of age, and a 55 per cent increased risk at age six. At age eight the increased risk was 61 per cent while at age 10 the increased risk was 37 per cent. The analysis is based on a scientifically-recognised checklist of child behaviour that assessed the study children's behaviour at two, six, eight and 10 years of age. Children that were breastfed had particularly lower rates of delinquent, aggressive and anti-social behaviour; and overall were less depressed, anxious or withdrawn. With adjustments for factors such as the parents' socio-economic situation, their education, their happiness and family functioning, children that were breastfed for at least six months were still at lower risk of mental health problems.

Our research has a particular focus on preventable deaths including deaths attributed to Sudden Infant Death Syndrome (SIDS) in the Indigenous population. An analysis of the database between 1980 and 2001 showed a significantly increased risk of deaths attributed to SIDS for Aboriginal babies compared with non-Aboriginal babies. Working with SIDS and Kids WA, the Preventing SIDS in Aboriginal Communities project has used a grass-roots, community consultation approach which aims to develop better ways and processes of transforming research findings into policy and practice through the development of interventions to prevent SIDS. This is an exciting project involving non-Aboriginal and Aboriginal researchers, health professionals, community members and those working in areas of policy development, resource allocation and the development of health strategy.

In 2006, we initiated collaborations with Alaska and New Zealand to compare patterns and trends of deaths of Australian Aboriginal, Alaska Native and New Zealand Maori babies and children. This study is the first of its kind and will provide important information about the differing pathways to and causes of death in each of these populations.

operators, provides age-appropriate books to families along with story-telling sessions and encourages general early literacy," she said

"These initiatives bring families together, teach parents the importance of reading to their children and promote book awareness."

To date, the project has received positive feedback from families and agencies alike and each year, the reach and capacity to improve literacy across the region grows.



Early literacy programs have improved outcomes for children in the Mirrabooka community.

## Understanding disability

	About	Facts and stats
Rett syndrome	Rett syndrome is a relatively rare but serious neurological disorder that usually affects girls. The clinical diagnosis has often been uncertain in early childhood as the symptoms may be confused with those occurring in other disorders such as autism, cerebral palsy and developmental delay.	Rett syndrome affects around one in every 10,000 female births in Western Australia. Mutations in the <i>MECP2</i> gene on the X chromosome have been identified as a cause of Rett syndrome. There is no known cure for Rett syndrome.
Alcohol and Pregnancy	Fetal alcohol spectrum disorder (FASD) is an umbrella term that describes the range of effects of maternal alcohol consumption during pregnancy. Fetal Alcohol Syndrome (FAS) is a diagnosis that is included in FASD and is characterised by physical defects and disabilities, the main features being cranio- facial abnormalities, prenatal and/or postnatal growth deficiency, and evidence of damage or dysfunction of the central nervous system. The consequences of FAS are lifelong.	<ul> <li>FAS was first identified in the 1970's.</li> <li>It is a preventable condition.</li> <li>Data from the Western Australian Birth Defects Registry suggest a birth prevalence of 0.18 per 1,000 live births:</li> <li>0.02 per 1,000 non-Indigenous live births</li> <li>2.76 per 1,000 Indigenous live births.</li> </ul>
Hypospadia	Hypospadia is a urogenital birth defect that affects boys, where the opening of the penis forms on its underside rather than its tip. Hypospadias can be corrected with surgery.	It is the second most common birth defect in Western Australia. One in every 118 West Australian boys is born with hypospadia each year:
Cerebral palsy	Cerebral palsy refers to a collection of diseases with the common clinical features of motor impairment resulting from damage to the brain before birth, around birth or in early childhood. Cerebral palsy can be accompanied by epilepsy and defects in intellect, vision, hearing and speech.	Cerebral palsy is the most common physical disability in children. For every child under the age of 18 years diagnosed with cancer, there are three with cerebral palsy. For most, the cause is unknown. There is no pre- birth test. There is no known cure for cerebral palsy - it lasts a lifetime.

### **SPOTLIGHT ON** Folate and neural tube defects

Institute Professors Fiona Stanley and Carol Bower were part of the international team that made the important discovery that increasing the vitamin folate before and during pregnancy helps to prevent neural tube defects (such as spina bifida) in babies.

The pair are now passionate advocates for mandatory fortification of flour with folate after it became apparent that education campaigns were not making as large an impact as hoped.

"We've had voluntary fortification and education campaigns over the past 16 years to encourage women to take folic acid supplements, yet the levels of neural tube defects have only dropped by 30 per cent when we know this figure could be as high as 70 per cent," said Professor Bower.

Professor Stanley said the mandatory

fortification of flour or bread with folate will ensure that many more women get enough folate to protect their babies from devastating neural tube defects such as spina bifida.

"Mandatory fortification is already a reality in more than 40 other countries including the United States and I think Australian families have a right to expect the same health benefits," Professor Stanley said.

#### **Our research**

During 2006, the fourth follow-up questionnaire was sent to Australian families of girls with Rett syndrome for completion via mail or over the internet. The information collected forms the basis of our AussieRett study, a population-based study following Australian girls born with Rett syndrome since 1976. Genetic and clinical data are also collected and 127 bone densitometry assessments have now been completed.

We continue to manage an international database known as InterRett, which collects data from families and clinicians around the world. During 2006, more than 50 new families joined the database following an international Rett syndrome family conference in San Fransisco and around 300 new French families were added following a meeting with representatives from a children's hospital in Paris and the French Rett syndrome family association. This increases the database to contain information for more than 1100 people with Rett syndrome from 30 countries.

Our previous research identified that health professionals have a lack of knowledge about alcohol use during pregnancy and its consequences. The need for quality resources was identified and during 2006, we developed an information pack designed to support the knowledge and advice of health professionals about alcohol use during pregnancy. To help guide the content of the information pack, focus groups were held with a range of health professionals including nurses, Aboriginal health workers, allied health professionals, general practitioners and obstetricians in both metropolitan Perth and country areas and information was also collected from Aboriginal and non- Aboriginal women of child-bearing age about communication of alcohol information during pregnancy. The information pack contains a comprehensive booklet and a fact sheet for health professionals, wallet cards for distribution to women and a desk calendar. Initial testing of the pack showed the resources were well-received and suitable for use by health professionals. The packs will be distributed and evaluated during 2007.

We also looked at alcohol consumption during pregnancy of a 10 per cent random sample of all births in Western Australia during 1995 to 1997. Most women (80 per cent) reported drinking alcohol in the three months before pregnancy, with 59 per cent drinking alcohol in at least one trimester of pregnancy. Women generally reduced their average alcohol consumption and the number of standard drinks on a typical occasion as their pregnancy progressed, although 10 to 14 per cent were drinking in excess of the current guidelines for pregnancy. With almost half (47 per cent) of the pregnancies unplanned, it is important that all women of child-bearing age are aware, well before they consider pregnancy, of the risks of drinking alcohol during pregnancy so they can make informed decisions about their alcohol consumption in pregnancy.

Our research has involved determining the prevalence and trends of hypospadias in WA between 1980 and 2000. Findings showed a total of 1788 cases were registered and that the rate of hypospadias increased by two per cent per year from 28 per 10,000 births in 1980 to 43 per 10,000 births in 2000. In particular, the rate of moderate or severe hypospadias (which occurs in 11 per cent of all cases) almost doubled. There was also a consistent rise both in babies diagnosed with isolated hypospadia and babies who also had other co-existing anomalies, and infants with co-existing anomalies were more likely to have a severe form of hypospadia.

We are now investigating possible maternal and paternal risk factors that may be associated with hypospadias and also looking at the health status, outcomes and health service utilisation of boys with hypospadias and those who have had surgical repair in WA between 1980 and 2003.

During 2006, we made significant progress with the Australian Cerebral Palsy Register, a collaboration of Cerebral Palsy Registers in all States and Territories in Australia, which has been coordinated by the Institute since its inception in 2002. Almost 100 per cent of the Australian population is now covered by State and Territory cerebral palsy registers with only the Northern Territory still seeking funding. We are also designing a standardised method of recording clinical data to ensure that cerebral palsy is classified consistently between States. The newly-developed Cerebral Palsy Description Form was trialled nationally in 2006, along with a motor assessment DVD which forms the basis of a reference and training manual for ongoing use. We continue to maintain the Western Australian Cerebral Palsy Register, one of the longest-standing cerebral palsy registers in the world, which collects data to monitor trends in cerebral palsy overall and in groups such as pre-term or multiple births, and to facilitate studies into the causes of cerebral palsy.

Neural tube defects affect almost one in every 700 babies and occur when there are problems with the development of a baby's brain, skull and spinal cord during the first six weeks of the pregnancy.

Many babies with a neural tube defect die early in life or have lifelong disabilities such as varying degrees of paralysis of the legs and incontinence of the bowel and bladder.



Professor Carol Bower, Mr Lyall Thurston and Professor Fiona Stanley all received a Leadership Award from the Folate Fortification Initiative.

## Outstanding people



Why would some of Australia's leading child health researchers choose to work in Western Australia?

We can't believe that we still get asked that question!

WA has abundant **resources** -- in what many consider to be the world's best population databases, a number of which were established by the Telethon Institute for Child Health Research. Through WA's unique Data Linkage Unit, these databases can be linked to information about health, education and justice outcomes, without identifying individuals.

We're also richly blessed by our **community** -- a stable, motivated population that actively supports and participates in our research, enabling us to undertake very large, long-term studies of children and their families.

WA is geographically very close to our Asian **neighbours** -- we're very excited by a range of collaborative research projects ranging from infectious disease, to environmental health and educational outcomes.

We have an outstanding **leadership** team of senior scientists -- led by 2003 Australian of the Year Professor Fiona Stanley, the Institute has attracted leaders in their fields from around Australia and around the world.



left to right: Carol Bower, Nick de Klerk, John Finlay-Jones, Robert Ginbey and Prue Hart.

#### Carol Bower MBBS MSc PhD FAFPHM DLSHTM

#### Head of Epidemiology

Clinical Professor, University of Western Australia. Professor Bower has been a research scientist at the Institute since its 1990 opening. She established the internationally recognised Western Australian Birth Defects Registry, is a Fellow of the Australian Faculty of Public Health Medicine and holds a Principal Research Fellowship from the National Health and Medical Research Council.

#### Nick de Klerk BSc MSc PhD

#### Head of Biostatistics and Genetic Epidemiology

Adjunct Professor, University of Western Australia. Professor de Klerk joined the Institute in 2000 after leading the Occupational Respiratory Epidemiology Group in the Department of Public Health at the University of Western Australia for 10 years. Before that he gained broad experience in biostatistics and epidemiology both in Western Australia and England.

#### John Finlay-Jones BSc(Hons) PhD FAIBiol FASM

#### Assistant Director

Adjunct Professor, University of Western Australia, and Emeritus Professor, Flinders University of SA. A science graduate of UWA, Professor Finlay-Jones spent 25 years at Flinders University, most recently as Head (Executive Dean) of the Faculty of Health Sciences, before joining the Institute in 2003. He has been President of the Australian Society for Medical Research (1990), the Australian Society for Microbiology (1996-1998) and the Australian Institute of Biology (1999-2001).

#### **Prue Hart** BSc(Hons) MSc PhD

#### Head of Inflammation Laboratory

Principal Research Fellow, NHMRC and an Adjunct Professor at the University of Western Australia. Professor Hart joined the Institute in July 2003 from Flinders University in Adelaide where she had been in the NHMRC Fellowship scheme since 1991. She has previously worked at University of Queensland (Royal Brisbane Hospital), Rigshospitalet in Copenhagen and the University of Melbourne (Royal Melbourne Hospital).

#### Robert Ginbey BA BEd Grad Dip Public Sector Mgt MACE

#### Head of Division of Administration and Corporate Services, Company Secretary

Mr Ginbey joined the Institute in 1995. He has taught history and economics in Western Australia and Papua New Guinea and has worked as a senior policy officer and senior manager of corporate services and strategic planning for both the commonwealth and state governments.

## Senior staff



left to right: Colleen Hayward, Pat Holt, Ursula Kees, Deborah Lehmann and Bruce McHarrie.

#### Colleen Hayward BEd BSc

#### Manager, Kulunga Research Network

Associate Professor, Curtin University. Colleen is a senior Noongar woman with family ties throughout the South-West of Western Australia. She has an extensive negotiation, advocacy, policy and management background in a range of government and non-government areas and was previously deputy Chief Executive Officer of the Aboriginal Legal Service of WA. Other experience covers areas including health, education, training, employment and housing.

#### Pat Holt PhD FRCPath(UK) DSc FAA

#### Deputy Director, Head of Division of Cell Biology

Professor Holt established the Division of Cell Biology in 1990. He is currently Senior Principal Research Fellow, NHMRC and holds a Professorship at the University of Western Australia. Previous appointments include Acting Director, Clinical Immunology Research Unit, Princess Margaret Hospital for Children and Research Fellow, Institute of Environmental Hygiene, University of Gothenburg.

#### Ursula Kees Dip Phil II PhD

#### Head of Division of Leukaemia and Cancer Research

Adjunct Professor, University of Western Australia. Professor Kees has been a researcher at the Institute since its inception in 1990. She is interested in the molecular genetic mechanisms leading to cancer in children. In collaborative studies with the Oncology Total Care Unit at Princess Margaret Hospital for Children, she developed new methods for cancer diagnosis.

#### Deborah Lehmann MBBS, MSc

#### Head of Infectious Disease Epidemiology Research

Clinical Associate Professor, University of Western Australia. Professor Lehmann joined the Institute in 1998 after 18 years at the Papua New Guinea Institute of Medical Research where she headed a multidisciplinary Pneumonia Research Program. In November 2004, Deborah was appointed an Adjunct Associate Professor at Curtin University of Technology. She provides expertise in infectious disease epidemiology and Indigenous health.

#### Bruce McHarrie BCom CA

#### Chief Financial Officer

Bruce McHarrie joined the Institute in 1999. He was previously an Assistant Director in the Bioscience Unit at Rothschild Asset Management in London and before that was with Coopers and Lybrand, also in London. Bruce has financial and executive management responsibilities as well as develops the Institute's commercialisation opportunities.

## Senior staff



left to right: Peter McMinn, Sven Silburn, Peter Sly, Wayne Thomas and Steve Zubrick.

#### Peter McMinn BMed Sc(Hons) MBBS PhD FRCPA FRCPath DipRACOG

#### Head of Division of Virology

Peter McMinn is a virologist and Clinical Associate Professor, Discipline of Microbiology, School of Biomedical and Chemical Sciences, University of Western Australia. He spends half of his time in research at the Institute and half as a clinical virologist at Princess Margaret Hospital for Children.

#### Sven Silburn BSc(Hons) MSc(Clin Psych) MAPS

#### Director, Centre for Developmental Health

Professor Silburn joined the Institute in 1991. Professor and Director, Centre for Developmental Health, Curtin University of Technology, Sven completed his clinical training in South Africa and worked in clinical child psychology for the Health Department of Western Australia. He chairs the Ministerial Council for Suicide Prevention and is a principal investigator on the WA Aboriginal Child Health Survey.

#### Peter Sly MBBS(Melb) MD(Melb) DSc(UWA) FRACP

#### Head of Division of Clinical Sciences

Professor Sly established the Division of Clinical Sciences at the Institute in 1991. Professor Sly is currently Director of the WHO Collaborating Centre for Research on Children's Environmental Health and a Respiratory Physician, Princess Margaret Hospital for Children. He is also Professor, School of Paediatrics and Child Health, University of Western Australia and Adjunct Professor, School of Public Health, Curtin University of Technology.

#### Wayne Thomas BSc Hons PhD

#### Head of Laboratory Sciences, Head of Division of Molecular Biotechnology

Professor Thomas currently holds a Professorship at the University of Western Australia and is a Senior Principal Research Fellow, NHMRC. He has been division head since 1990. He has previously worked at the Medical Research Council, Clinical Research Centre London and at the Walter and Eliza Hall Institute for Medical Research in Melbourne.

#### Stephen Zubrick MSc AM PhD

#### Head of Division of Population Sciences

Professor Zubrick is a Senior Principal Research Fellow in the Institute and holds a Professorship at Curtin University's Centre for Developmental Health. He has worked in various mental health settings. He chairs the Consortium Advisory Group, National Longitudinal Study of Australian Children, sits on the Commonwealth Mental Health Promotion, Prevention and Early Intervention Working Party, and is a member of the Federal Government Australian Council for Children and Parenting.

## 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.

### 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. Phylogica is applying its Phylomer® peptides to block common pathways in inflammation in conditions such as rheumatoid arthritis, allergies, diabetes, stroke and burn injury.

### 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.

### Notre Dame University

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

### 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. We are involved in the Papua New Guinea pneumococcal conjugate vaccine project, and host PNGIMR staff and students for exchange visits.



**above:** June Hamena (second from left) and Ulo Jasipa (centre) spent two weeks at the Institute during an exchange visit. They are pictured with Professor John Finlay Jones, Professor Deborah Lehmann and Mr Robert Ginbey.

### Passionate people Dr Sue Byrne



Sue Byrne is a lady of many talents.

She has been a ballet dancer, winning a scholarship to the Bejart Ballet School in Brussels when she was 16.

She's been a high school teacher.

In 1984, Sue won a UWA Full Blue (the highest award of the UWA Sports Council) for representing Australia in rhythmic gymnastics.

And she's a mother of four beautiful children.

Sue is also a clinical psychologist and leads the childhood obesity research at the Institute.

Sue's main area of interest is eating and weight disorders.

"I am really passionate about helping people to get better as quickly as possible," she says.

"I've been interested in eating and weight disorders since conducting my Honours research in the area of body image in adolescents." "Now, I want to develop and test better treatments for eating and weight disorders and use our findings to help prevent these problems developing in children, or to treat children who are already suffering."

The Institute's Childhood Growth and Development Study, headed by Sue, is collecting information from West Australian school children to identify the biopsychosocial factors that contribute to the development and persistence of childhood obesity.

Sue's research team, which she describes as enthusiastic and efficient, is assessing over 1500 children and their families.

"We've had great support from families all over metropolitan Perth," says Sue, who has been at the Institute since 2002.

Sue considers winning the Tracey Goodall Award for outstanding contribution to cognitive behavioural therapy in Australia as a highlight in her career, along with her UWA Postdoctoral and NHMRC Fellowships, and the five years completing a Doctor of Philosophy at Oxford University in the UK.

"I was successful in winning a Wellcome Trust prize to allow me to study there. We lived in beautiful Oxford in a University college for nearly five years and had two of our four children over there," she says.

Sue is passionate about her work and wants to keep at it for some time yet.

"I want to continue doing what I love - a combination of research, teaching and clinical work."

"I also love being with my family and running around after the kids."

Sue has also recently pulled on the pointe shoes again and recommenced ballet classes.

"I love classical ballet and its great to be back at classes after six years and four children."

### Passionate people Dr Alex Beesley



Dr Alex Beesley feels that a driving force for him is being in a job that makes a difference. And what could be more meaningful than directly helping the way children with leukaemia are treated in the clinic.

Alex came to the Institute in 2003 after spending more than five years in Sydney as a postdoctoral researcher and medical writer.

His background is in physiology. At Sheffield University in the United Kingdom, Alex completed his honours, PhD and two years of postdoctoral research in physiology before escaping the English winter to the warmth of Australia.

The move down under has been a good one for Alex.

His skills and expertise secured a senior role within the Institute's Division of Children's Leukaemia and Cancer Research, while Western Australia's great climate allows him to pursue his love of scuba diving, volleyball and outdoor activities.

As a Senior Research Officer at the Institute, Alex is responsible for the management of research into the mechanisms of relapse in children's leukaemia.

His research is looking at the identification of genes and pathways involved in drug resistance and clinical outcome in childhood leukaemia.

"We hope to find genetic markers that can predict patients at risk of relapse, and to understand the biological basis of such relapses."

"This will allow us to develop improved screening strategies that can be used to tailor therapies to individual patients."

"This will improve survival rates whilst at the same time reducing toxicity by providing more focused and effective treatment," he says.

Alex says that while the success rate

for childhood leukaemia is now very good, a large number of patients still relapse.

"The therapies used to treat leukaemia are harsh and are associated with both long and shortterm side effects," he says.

"By understanding the factors that contribute to patient relapse it should be possible to design improved therapeutic strategies for this disease."

So far, Alex and his team have had some success.

"We have identified gene-signatures from bone marrow capable of predicting relapse in two different cohorts of children with leukaemia."

His team recently won a grant from the Cancer Council of WA to study the function of specific genes thought to be involved with resistance to steroids, one of the most important drug classes for the treatment of leukaemia.

## 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.

Australia's National Health and Medical Research Council has developed a Statement on Consumer and Community Participation in recognition of the contribution that consumers can make to research, as well as their right to participate in research.

The Statement stipulates consumers and researchers should share a vision of working in partnerships based on understanding, respect and shared commitment to research that will improve the health of humankind.

In conjunction with the UWA School of Population Health, the Institute has employed a Consumer Research Liaison Officer, a unique appointment in Australia.

In this role, Anne McKenzie is developing processes to facilitate community and consumer partnerships and collaborations.

Achievements to date include:

- Development of a strategic plan for consumer and community participation which was endorsed by the Institute
- Conducting an audit of current consumer and community participation activities
- Holding workshops for staff and consumer/community groups
- The development and implementation of an Institutewide policy on consumer and community participation.

A major achievement during 2006 was the establishment of the Institute's Consumer and Community Advisory Council. Membership of the Council includes nine community members, five Institute researchers, the Institute's Director or her nominee and the Consumer Research Liaison Officer.

The Council is chaired by Ben Horgan from Arthritis WA and will provide important links between consumers, the community and researchers at the Institute. The Council will provide advice and expertise on consumer and community issues and priorities for research and valuable feedback on strategic planning and governance structures relating to consumer and community participation in research. In 2006, the Raine Study Reference Group was set up as a direct result of a consultation between researchers, families and study participants.

The Reference Group provides the opportunity for Raine Study participants to work with Raine Study staff and management in order to make study materials more suitable and relevant for teenagers.

Other research projects have also incorporated consumer and community participation into their research, in particular the Alcohol and Pregnancy Project, the Rett syndrome project and the Developmental Pathways in WA Children Project.



**above:** The Raine Study Reference Group with Raine Study teenagers (back row L-R): Rachael, Samantha and Jess (front row L-R) Scott, Jessica, Aislin, and Roland.

## Corporate and community partnerships



It is important to understand that great science takes time -- from the conception of an idea, to the rigorous collection of data, to the validation and implementation which in some instances can take five, 10 or even 20 years. Not unlike parents nurturing a child from infancy through to adulthood.

As a not-for-profit organisation, the Institute is dependent on donations from the community and the business sectors. In 2006 our research record and advocacy attracted tremendous support, with more than \$2.5 million received in fundraising income.

Our fundraising income represents the many ways in which the community can invest in the Institute. This includes bequests, corporate partnerships, foundation and trust grants, fundraising events, general donations or by providing probono skills and goods-in-kind.

The Institute would like to acknowledge the following partners who have provided critical support to our activities.



The following stories highlight **some** of our supporters in 2006 and their unique investment in the Institute.

### LONG TERM PARTNERSHIPS Channel 7 Telethon

Telethon is one of Western Australia's most loved children's charities. Since 1968, Telethon has raised over \$70 million for children and young people throughout Western Australia. In 2007, Telethon celebrates its 40th Anniversary.

Throughout the year, Telethon conducts a range of fundraising events culminating in a live 24-hour charity appeal - the Telethon weekend. The Telethon weekend has grown to become the most significant television charity appeal in Australia and the most successful fundraising event per capita in the world.

Telethon has partnered with the Institute since 1990 and continues to play an integral role in the ongoing success of the Institute. Each year, the Institute receives substantial funding from Telethon and this commitment is reflected in the naming of the Institute. Without the support of the Western Australian community and Telethon, the Institute would not be able to conduct the ground-breaking research into childhood diseases and disabilities that it does today.

### **CORPORATE PARTNERSHIP** Shell Australia

For the past three years, Shell Australia has supported the Australian Early Development Index (AEDI) project which measures the developmental progress and school-readiness of children within a community. During this time, more than 31,000 children from 54 communities across six States and territories have completed the AEDI.

Data provided back to the community helps identify areas of need and enables the community to take steps to improve services to foster healthy child development. Some examples of community action arising from participation in the AEDI project include local playgroups established for pre-school children, an Aboriginal kindergarten, a peer-led breastfeeding program and better support for teenage mothers.

The funding from Shell has also facilitated opportunities for the Institute to leverage additional funds which has provided for the ongoing support and further development of Australia's capacity to monitor early child development outcomes at a community and jurisdictional level.

### TRUSTS AND FOUNDATIONS Stan and Jean Perron Charitable Trust

Well-known West Australian philanthropists Stan and Jean Perron have been donating to the Institute for nearly 15 years. They have a keen interest in supporting exceptional postgraduate research students, the next generation of health and medical researchers. With the Perron's generosity, several awards are offered to the most outstanding PhD students at the Institute. Known as the 'Stan and Jean Perron Awards', they provide annual scholarship top-ups for the duration of a students PhD or performance awards to allow a student to attend an international conference or continue their studies.

### **COMMUNITY EVENT** St George's Day

The annual St George's Day Fundraiser began in 2003 when a group of English ex-pats, grateful for all of the opportunities available to them in Western Australia, came together to celebrate what is regarded by some as England's national day - St George's Day - and raise money for charities in WA.

Ever since, hundreds of people attend the St George's Day Lunch raising money for child health research. In 2006, the concept was expanded to include the Red and White Ball held on the Burswood foreshore.

This is an exceptional example of a community fundraising event with the ability to raise large amounts of funding for the Institute. The amount of time and effort put into organising this event is extraordinary and the Institute would like to warmly acknowledge the efforts and generosity of the St George's Day Committee.

### **PRO-BONO SERVICES** KPMG



**above:** *Ken Mesure from the St Georges Day lunch organising committee gets into the spirit of the festivities.* 

KPMG is one of the world's leading professional services firms. The Perth office generously conducts the Institute's annual auditing of the financial statements on a pro-bono basis and has been doing this since 1990. This service enhances the credibility and confidence in the information being reported to our stakeholders.

### BEQUEST Mr John Lillie

In 2006 the Institute received its largest ever bequest from John Lillie, who passed away in 2004 at the age of 88.

Mr Lillie's important gift has enabled the purchase of a critical piece of equipment for our childhood cancer laboratory. It will also enable the Institute to establish a prestigious five-year Cancer Research Fellowship to attract a high-achieving researcher to Western Australia to work in the Institute's internationally-recognised cancer research team.

We are so grateful to individuals such as John Lillie who have left a bequest to the Institute. Bequests are a wonderfully generous way of leaving a legacy to child health research – ensuring generations of young lives will be improved as a result of our research.

### **VOLUNTEERS** The Friends of the Institute for Child Health Research

The Friends of the Institute are a very important circle of volunteers, with a group in Perth and Margaret River, who act as advocates for the Institute in the wider community. The Friends provide crucial financial support to the Institute and just as importantly, raise awareness of the Institute's research activities and the need for funding.

'Friend-raising' and fundraising are important aspects of the Friends' goals. The Friends of the Institute host regular events and functions in their communities to raise money for child health research at the Institute. The Friends are proud to make meaningful and worthwhile contributions to many of the research projects at the Institute. This includes supporting child health research projects, providing scholarships for students at the Institute and funding professional development opportunities for some of our brightest young researchers.

### **PAYROLL DEDUCTIONS** Pitcher Partners

Pitcher Partners is a leading accounting and advisory firm in Perth which offers a payroll giving program to staff, with the Institute being one of the recipients chosen by employees.

Payroll deductions are a simple way for employees to donate regularly to charities directly through their pay. This system of donating provides a low cost, administratively simple way for a business to demonstrate its commitment ethically and commercially to the health and wellbeing of children in Australia. This in turn sends positive signals to investors, shareholders, employees and customers alike.

The Pitcher Partners workplace giving program provides the Institute with stable funding for core programs.

Fundraising has never been an easy task, and even in the boom times that are being experienced now in Western Australia, it is still an enormous challenge. There are many wonderful causes seeking donations. But it is our belief that children's health and wellbeing is one of the most crucial investments our society can make for benefits now, and into the future.

In the recent International Scientific Review of the Institute, we were advised by our peers that we will need an endowment fund of \$100 million to secure our future. At first this seems an unimaginable sum of money for a not-for-profit organisation to raise, but in the commercial world this type of capital base is understood as essential for an organisation to be competitive and successful on the global stage.

With the help of a group of prominent business leaders, who have outstanding networks and the commercial understanding of how to encourage investment, the Institute has begun to plan a fundraising campaign called the **Children's Future Fund** which will help build our endowment fund.

Research is expensive, but the human cost of disease and disability is far greater. If you share our belief that **EVERY CHILD** has the right to a healthy future, then the equation is simple.

### Donations will equal discoveries.

### Passionate people Dr Ingrid Laing



December 25, 2004 was a day of celebration for Ingrid Laing. Not only was it Christmas but after years of research, she had just submitted her PhD the day before.

Ingrid has been a familiar and friendly face at the Institute for nearly 12 years.

With long-established links through her PhD studies, Ingrid became an official employee in 2005 when she was awarded an Australian Respiratory Council Ann Woolcock Research Fellowship.

Ingrid's research is looking at the role of genetics in the development of acute lower respiratory tract infections in highly-susceptible infants.

"I first started in this area of research because the asthma research field was developing an interest in the role of early life respiratory infections on the development of asthma in children," Ingrid says.

"My PhD studies had focused on

the contribution of inflammatory genes to asthma and I was interested in how immune genes involved in the response to infections, affected immune development and susceptibility to these infections."

By accident during her PhD studies, Ingrid found a startling difference in the frequency of an anti-inflammatory gene variant between two populations with diverse ethnicities.

Further research by the asthma genetics team found a pattern of frequencies of immune gene variants in populations originating from very different climatic regions of the world.

"We found that populations originating from tropical climates had very high frequencies of genetic variants in inflammatory genes, with very low frequencies in populations originating from arctic climates," she says.

"This led to my research fellowship project working with a team of researchers to look at how high frequencies of genetic variants in immune genes in a population from a tropical climate, in this case in Papua New Guinea, would affect the development of the immune system, response to vaccines and susceptibility to respiratory infections."

Ingrid hopes her research will contribute to better treatments or intervention strategies for infections that still affect millions of children worldwide each year.

"I also want to help improve understanding of the balance between genetic, socio-economic and other environmental factors on the susceptibility of ethnically diverse populations to respiratory diseases."

With a love for travel, Ingrid jumped at the opportunity to spend three months at the Arizona Respiratory Center in the US during 2007.

"I hope to learn some new research methods in the US and bring these back to the Institute," she says.

## Chief Financial Officer's report

The International Scientific Review of the Institute in November not only reflected on the past five years but also, more importantly, contributes significantly to our planning for the coming years. At the conclusion of this important exercise, the Review Panel Chairman, Professor Don Roberton, encapsulated our current position with the statement "Many of the challenges that the Institute faces today are the challenges of success."

Those challenges are many and varied but almost all of them have a common link – financial resources.

An indication of our success is set out in the graph below, which shows the growth in our gross income since the year 2000. Gross income for this purpose includes research, operational and fundraising activities.

There are, of course, costs associated with these activities and one of the major challenges for the research sector is dealing with the shortfall between the funding provided by granting agencies and the total costs of undertaking research. For every research dollar received another 70 cents is required to cover the associated costs of facilities, services and direct and indirect research support. We currently derive approximately half this amount either directly from research contracts or indirectly from State and Federal Government funding sources. Income from fundraising is required to cover the balance and income from this source is far from predictable. One challenge of success therefore is to ensure we don't go broke in the process!

As I have said in previous reports, income from sources such as the State Government's Medical and Health Research Infrastructure Fund (MHRIF) is a critical component of our operational income. The quantum of that fund has not changed for some time, which clearly creates issues when trying to support a growing activity. In addition, there is frequently some uncertainty concerning its future existence. In 2006 the Institute received \$1.7 million from MHRIF - the return on investment to the State is significant even if the only measure used is the gross income generated by the Institute. However, in addition to this, and more importantly, are the benefits associated with preventing illness and disability in society. I would therefore continue to encourage the State Government to invest further in the MHRIF.

Many of the initiatives arising from the International Review will require sustained funding into the future. An



important source of such funds will be philanthropic support. To date all donations not tied to specific research projects are accumulated in what we refer to as our capital fund. In effect it is our "future fund", as the donated dollar is preserved in perpetuity and consequently the investment income that it generates funds future initiatives in a sustainable way.

The Institute's capital fund currently stands at approximately \$20 million. The income from this fund is already supporting research in many forms and typically in a way that will lead to growth in research activity and capability. In isolation it is of a significant size and we are indebted to our many supporters including, of course, Telethon. However, in comparison to the activity as measured by the graph of income and the plans for the future, it is inadequate to meet our needs and will clearly need to grow substantially. In fact, the International Review Panel recommends that the fund should be \$100 million.

Raising funds of this quantum will present its challenges, but over time will be achieved. Success in this endeavour is in fact essential if we are to have a secure and productive research institute and deliver on our stated aims. To this end we will be launching our Children's Future Fund campaign in 2007 and seeking the support of corporations and the community.

Finally, people make it all happen – we have excellent researchers with excellent research support. I would again like to thank the administrative and research support personnel for their important contribution.

#### Bruce McHarrie

### Passionate people Dr Merci Kusel



As a general practitioner, Dr Merci Kusel has witnessed first-hand an increase in the prevalence of asthma, eczema and other allergic diseases and the impact these diseases have on patients and their families.

It sparked her interest in finding out more through research.

"I wanted to be at the coal face of research into these conditions."

"Also, in doing research work parttime, I was trying to create and achieve a better balance in my life because full-time general practice can be emotionally challenging and demanding," she says.

"A good balance in my life means I still get a buzz out of what I do, stay happily married and can spend time with my three beautiful children and the dog."

Merci is the coordinator of the Childhood Asthma Study, which has closely followed a cohort of more than 350 children for the last 10 years.

The aim of the study is to see if infections during the early years have an impact on allergic diseases like asthma.

"The children were seen whenever they had a respiratory infection in their first five years and we performed over 5000 home visits as well as annual assessments which included clinical examination, allergy and lung function testing and collection of blood samples."

Merci is in the process of analysing the data from the first five years of the study and writing up the results which she hopes will enable researchers to learn more about the development of the immune system and allergic disease.

She is aiming to complete the 10year follow-up by June 2008.

"We have a fantastic group of

children and l've developed a wonderful rapport with them and their families," she says.

"As the children approach their tenth birthdays, I hope we can maintain the excellent retention rates achieved during the five-year follow-up."

Merci has a growing interest in children's environmental health in developing countries and will travel to China in 2007 to look into establishing collaborative research projects in this area.

Merci is a very focused and driven person with a thirst for knowledge.

With a medical degree and PhD under her belt, she is now nurturing her learning in other areas - she is learning French, trying to achieve a reasonable standard on the piano and is also brushing up on her Mandarin.

"I practice in the car and often find people giving me strange looks when they drive past," she laughs.

## Commercialisation and biotechnology



The application of our research findings to improve the health of children, adolescents and families is a key aim of the Institute.

The Institute's patent portfolio currently consists of 34 patent families of which 25 are active. Of those, 16 have been either licensed or assigned to other entities. In 2006, five National phase, one Patent Cooperation Treaty (International) and four provisional patent applications were lodged.

### Cancer

Our division of Children's Leukaemia and Cancer Research headed by Professor Ursula Kees, has identified a set of genes that identifies childhood leukaemia 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.

### Asthma / Allergy

Researchers headed by Professor Pat Holt in the Division of Cell Biology, have identified a suite of genes that could provide a method of diagnosing, predicting the development and monitoring the treatment of an allergic disease.

### Respiratory System Function

Airway function is the focus of an invention being developed in the Clinical Sciences Division led by Professor Peter Sly. 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. It is expected that the device will allow babies to be tested without the need for sedation.

### Viral Infections

A large number of viruses (including Hepatitis C) 'hijack' cellular translation machinery to prevent host cell protein synthesis and enhance translation of viral proteins. Researchers at the Institute have developed a method of screening for inhibitors of viral translation.

### Contract Research

The major component of our commercialisation activities is in contract research.

The Vaccine Trials Group (VTG) is 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 is involved in epidemiological studies, clinical trials of new and existing vaccines and in basic laboratory research necessary to design new vaccines.

The VTG undertakes research on behalf of a number of pharmaceutical companies including 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 development of drug candidates for the treatment of inflammatory conditions drawn from its exclusive library of Phylomer® peptides.

2006 highlights:

- Phylomer® stroke drugs were found to have a wider application, being effective in reducing brain damage after head injury
- Delivered on first milestone in collaboration with Opsona Therapeutics. 37 unique Phylomer® peptides were identified that bind to proteins that play a key role in inflammatory diseases
- Awarded grant to develop Phylomer® drugs to halt brain damage by the Western Australian government under its Neurotrauma Research Program.

### Advanced Diagnostic Systems

Our second spin-off company is Advanced Diagnostic Systems Pty Ltd (ADS). Formed in 2003, it is focused on the development of asthma and allergy prognostic and diagnostic systems. To achieve this aim, funding was secured from a UK-based investor and the Institute assigned the relevant patented technology into the company.

The funding and research work concluded, as scheduled, in December 2006 and the results have been very positive. The next major challenge is to translate those results into a commercially-viable product and to that end, we are collaborating with a major international diagnostics company.



**above:** Phylogica's unique set of Phylomer® peptides are small protein fragments that block protein-protein interactions in cells that lead to disease.

## Committees of the Board



#### **Appointments and Promotions**

Kevin Campbell AM (Chair) Carol Bower Nick de Klerk Julia Emmerson John Finlay-Jones Bruce McHarrie Fiona Stanley AC Wayne Thomas Stephen Zubrick

#### **Building Artworks**

Harvey Coates AO (Chair) Sir James Cruthers Tammy Gibbs Robert Ginbey Fiona Stanley AC Thierry Venaille

#### **Capital Fund**

Kevin Campbell AM (Chair) Harvey Coates AO David Berinson Bryce Denison Robert Ginbey Rudi Gracias Bruce McHarrie Fiona Stanley AC

#### Development

Danielle Blain Alison Bugno Mark Ceglinski Harvey Coates AO Matthew Cooper Hon Richard Court AC Tammy Gibbs Trevor Hunt John Langoulant Margie Livingston Liz Mansell Peter Mansell Bruce McHarrie Heather Monteiro James Smedley Fiona Stanley AC

#### Finance

Keith Jones (Chair) Kevin Campbell AM Sheree Dixon (from March 2006) Robert Ginbey John Langoulant Bruce McHarrie Monica Spalding (to March 2006) Fiona Stanley AC

#### Intellectual Property/ Commercialisation

Graham Mitchell AO (Chair) Stuart Boyer Simon Carroll Nick de Klerk Patrick Holt Bruce McHarrie Paul Watt

#### Scientific Advisory

Louis Landau AO (Chair) Angela Alessandri Harvey Coates AO John Finlay-Jones Robert Ginbey Colleen Hayward Peter Le Souef Richard Loh Bruce McHarrie Susan Prescott Richard Prince Fiona Stanley AC Geoff Stewart Wayne Thomas Charles Watson AM

## Management/Operating structure



### Passionate people Brett Robinson



Brett Robinson was a new recruit to the Institute in 2006.

Responsible for managing the Institute's information technology needs, Brett says IT and computing have always come naturally to him, even as a child.

"As a youngster, I got bored with computer games and started to program my own," he says.

"This led me to write various other software programs to make my daily tasks easier."

As he got older, Brett started to explore his creative side, learning about multimedia, 3D graphics and web design.

But his easy-going personality and good communication skills steered him towards a career in IT management.

In his short time at the Institute, Brett has already made some big changes.

An integrated email and calendar system has been implemented, new servers have been installed, security measures have been reviewed and upgraded and a new operating environment has been designed to ensure better information sharing across PC, Mac and Linux systems.

"I want to keep the Institute at the leading edge of IT, whilst still keeping best-practice and industry-standard solutions in place," Brett says.

"With the IT industry forever evolving, it has a large role to play in assisting medical research and my goal is to ensure the Institute has the best IT solutions for its needs."

Brett also has a strong commitment to customer service.

"I'm passionate about providing excellent levels of service to customers," he says.

"We have implemented new processes to improve the level of

service to researchers. This has included establishing an IT help desk and an electronic system for logging and tracking IT jobs and dedicated staff to address both the PC and Mac needs of the Institute."

"I want to help people and always feel best after helping someone with their IT needs."

It would come as no surprise that away from the office, Brett loves the latest technology 'gadgets and toys'.

"I have a real desire to always know and learn the newest technologies. I forever have a need to know what is around the corner and how it can be used to enhance daily tasks," he says.

In his spare time, Brett still dabbles in computer graphics and design but also enjoys watching AFL football and the V8 Supercars.

And he is kept busy organising the Institute's social club calendar, having taken on the role of Co-President.

## Administration and Corporate Services

The Administration and Corporate Services Division strives to provide high quality services to support and enhance our research teams. The Division comprises approximately 12 per cent of the total population of the Institute, which now stands at more than 400 people.

Our priorities in 2006 included:

- Planning and preparations for the third International Scientific Review
- Planning for the potential relocation of the Institute to a new site, co-located with Princess Margaret Hospital for Children
- Strategic planning to understand and meet the corporate needs of the Institute
- Capacity building within the administrative and corporate services managers and staff associated with the Staff Performance and Development System.
- Strategic reviews (undertaken or in planning): Population Sciences Confidentiality Policy, Privacy, Consumer and Community Policy and Council, Institute Induction Policy and Procedures, Records Management and Information Management, Triennial Review of the Animal Ethics Committee, Needle Stick Injuries and other Emergency Procedures, Risk Analysis and Risk Management, Directorate Review, and Service Agreements with external collaborating research groups.
- Executive support and contribution to: The Board and its Committees; the Friends; the Executive; the Appointments and Promotions Committee; the IT Steering Committee; the Occupational Safety and Health Committee; the Animal Ethics Committee; the Animal Research Management Committee; the House Committee; the Student Reference Group; the Administration Managers' Forum; the Population Sciences Management Forum; and the Social Club.

To maintain our high level of support we welcomed five new managers to our team: Finance Manager, Sheree Dixon; IT Manager, Brett Robinson; Public Relations Office Manager, Tammy Gibbs; Corporate and Community Relations Manager, Sarah Fordham and Information Services Manager, Katherine Whipp.

As our Institute continues to grow in size and stature, we look forward to continuing to develop innovative ways to provide the best support for child health researchers.



**above:** Building and Operations Manager Dr Thierry Venaille during an emergency fire drill.

## 2006 - The year in brief

Australian competitive grants7,067,38624.7International competitive grants2,119,5947.4
International competitive grants 2,119,594 7.4
Other competitive grants 540,446 1.8
Government contracts 3,998,608 14.0
Commercial income 3,796,895 I 3.3
Other grants 2,292,150 8.0
Miscellaneous income 216,359 0.8
Investment income 2,000,170 7.0
Donations, fundraising, bequests & sponsorship 2,684,873 9.4
Research support 3,888,813 13.6
Department of Health WA 1,648,131
University affiliations I,190,422
Other 1,050,260
Gross income 28,605,294 100
Deferred income (2,499,373)
Net Income 26,105,921
EXPENSES
Scientific research 16,288,997 66.7
Research administrative and building services 5,711,107 23.4
Depreciation and provisions 2,423,449 9.9
Total 24,423,553 100
NET PROFIT 1,682,368

STAFF AND STUDENTS	2006	2005	% change
Total number of staff as at December 31 (paid and seconded)	335	325	3.1%
Total number of honorary and visiting scientists during the year	68	63	7.9%
Total number of postgraduate students during the year	75	52	44.2%
TOTAL	478	440	8.6%

## Research income

Australian Competitive Grants	
	471.000
Australian Research Council	461,899
National Health and Medical Research Council	6 602 987
National Health and Health Research Council	0,002,707
	7,067,386
International Competitive Grants	
Cystic Fibrosis Foundation Therapeutics Inc	154,525
International Rett Syndrome Association	58,430
National Institutes of Health	1,637,267
Wellcome Trust, UK	269,372
	2,119,594
Other Competitive Grants	
Actime Foundation of Western Australia	27 424
Carrer Council of Western Australia	39 95 1
Child Health Research Foundation	89.563
Healthway	383,508
,	540.444
	540,446
Government Contracts	
Western Australia	
Department for Community Development	73,000
Department of Corrective Services	135,950
Department of Education and Training	128,320
Department of Health	1,599,771
Department of the Premier and Cabinet	289,091
Office for Children and Youth	36,000
Office of Science and Innovation	886.480
Miscellaneous	18,057
Other	
Office of Aboriginal Health, Family and Social Policy, Northern Territory	135,000
Federal	02.002
Department of Family, Community Services and Indigenous Affairs	93,892
Office for Aberianal and Terror Strait Islander Health	47,545
	173,071
	3,998,608
Commercial Income	
Advanced Diagnostic Systems Pty I to	805.162
ALK-Abelo A/S	88,000
Amgen Inc	20,367
CSL Limited	612,066
GlaxoSmithKline Australia Pty Ltd	457,583
MedImmune Inc	22,500
Miscellaneous - Australian commercial	49,024
Phylogical Linguist of	13,705
PPD Development	1,108,201
Rio Tinto Services Ltd	429,500
Roche Products Pty Ltd	15.000
UCB S.A. Pharma	3,000
Wyeth Australia	47, 77
Wyeth Pharmaceuticals Inc	23,660
	3,796,895
Other Grants	-,
	10/ 002
Australian Pandiatris Survillance Unit	406,803
	40,000
Children's Leukaemia and Cancer Research Foundation	342 080
Curtin University of Technology	120.591
Edith Cowan University	28,607
Friends of the Institute for Child Health Research	16,300
Mission Australia	27,273
Murdoch University	6,024
Oxiam Australia Teletre	30,000
The Smith Family	30,000
The University of Western Australia	
Thoracic Society of Australia and New Zealand	40,000
	10,000
	2,292,150
Miscellaneous income	216 350
	210,007
ΤΟΤΑΙ	20.031.438
IVIAL	20.031.130

### Our supporters



Our supporters know that **every child** should have 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 enabling our scientists to conduct the best research possible to make a **brighter future for every child**.

Your support is, as always, greatly appreciated.

#### Donations

Jo Abbott acQuire Technology Solutions AEM Group Richard Alder Allergy Research Foundation Ambrosini Professional Placements Apache Energy Limited lillian Archibald A & M Atkins Australian Stock Exchange Scott Ayles Azure Ćapital P/L D & S Baker Paul & Cathy Ballazdin Lara Bandarian Bankwest Broker Distribution Alex Baptista lason Barrow Joan Bereyne

David Berinson Bethesda Hospital Alex Beesley Sarah Beveridge Joelene Bizzintino John Blake Blakiston & Crabb Carol Bower Stuart Bover Elizabeth Bozanich Sue Bradbury Sally Breeze Jaron Bresland R & R Bricker Rose Briggs Marianne Brockwell Jean Brodie-Hall M Broswan John & Jean Brown Alison Bugno Joy Capra

Nichole Carlyon Shane Cassey Bill & Wendy Castleden Mark Ceglinski Channel Seven Telethon Stephen Chard A Chatfield Kim Clark Janine Clayton Clifton Hills Primary School Harvey Coates AO Cathy Cole Marjorie Collins Craig and Lyn Colvin Margaret Coten Kempton Cowan Kevin Craigue Sir James and Lady Cruthers Paula Cunningham Cystic Fibrosis Association Heather D'Antoine

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Wendy Later Crystal Laurvick Kevin Lay Kirsty Lee John Lennon Jianghong Li Margie Livingston Llewellyn Family Mark I ord Lucy Henry & Patrick Louden Lycopodium Ltd Murray & Lesley Maff Cameron Manifold Geoff Mansfield Cat Marcody Dot Marie Jessica Markow Donna Martin Ken Martin Hazel McBride Michael McCall Judy McCarthy Margaret McCarthy Malcolm McCusker Ken McHarrie Peter McKerracher loyce McKirdy . Alana McVeigh Gillian Meecham A & J Miaris Kate Miller Colin & Karen Mills Mining People International Amanda Morcom Colleen Moylan Bill Muir Angie Munday Graeme Murphy Elizabeth Murray Manh Nguyen John Nietfield . Lyn Nixon Iohn Nolan Margaret Nowak Elizabeth O'Brien Kirsty Officer Geoff Ogden Colleen O'Leary Orbital Corporation Tom O'Rourke R & J Outhwaite Neville Owen Charles Oxnard Anthony Packer Ron Packer Jessica Padman Judy Paish Margaret Palmer George Panayotou Rani Param Trevor Parry Wal Pausin Elaine Pavlos Harold Payne Jan Payne Glenn Pearson Stan & Jean Perron Michael & Rhonda Perrott Shelley Petruzio Pickles Auctions Catherine Pienaar

Josephine Pittman PLAN Australia Sylvia Plumley Paul Poon L Porter Cecilia Prele Princess Margaret Hospital Anne Pugh Pump N Seal Claire Putland Margaret Pytte Tihan Radanovich Judy Rahn Abraham Rane Geoff Rasmussen Gail Reading Retirees WA Inc Rett Syndrome Australian Research Fund Elke Riekmann Kelly Robb R Roberts Leila Robertson Brett Robinson Susan Robinson Alan Robson G Rodie Cal Rogers Marjut Ropenen Royal Automobile Club of Western Australia Peter Saunders John Schaffer Mena Scott Hon Barbara Scott MLC Jackie Scurlock Brian Searles Ellen Seymour David Sharbanee Melanie Sharpham Shell Geelong Refinery lo Short Nicholas Sloan Graeme & Ros Smith Grant Smith Miranda Smith SMWC Kurt Sotzik Anne South South Technical Services Monica Spalding Sean Spence St George's Day Group St Mary's Anglican Girls School Fiona Stanley AC Brian & Natalie Stanley Campbell Stewart Virginia Stone Mark and Kirk Strathern Erna Stratton John Strijk Devinda Suriyaarachchi Helen Summers John & Anita Summers Swanleigh Community School Richard Tai Paul Tait Maxine Talbot Robyn Tamke Cindy Thamrin

Wayne Thomas Sue Thompson Chris Thorn Gillian Treichel John Upham Hendrik Valom Peter Van Houwelingen Bethany Veitch Thierry Venaille Antonio Versace Tanja Visosevic WA Paediatric Diabetes & Endocrinology Ltd Bruce Wainwright Leanne Walker Steven Walsh **B** Walters Kathryn Webb Kay Webse Mathew Welch Wesfarmers Ltd Western Square Dancers Club Westfield Ltd Jo Wheatley Olivia White Matthew Wikstrom Forreste Williams Gary Wilson Leila Wilson Kaye Winfield Winnie Wolf Diane Wood Margaret Wood Ian Woolley Julie Wyllie Wayne Zagami Deidra Young Guicheng Zhang Graeme & Ros Zosky

#### **Gifts in Kind**

Adventure World AQWA Charlotte Blackley John W Byrne - Notary Public Disability Services Commission (Darlington and surrounding suburbs) The Honda Foundation Honda North J Mills PathWest A & M Prior Quest Apartments (Subiaco)

#### Bequests

Kathleen Banfield Margaret Mills John Lillie Francis Longhurst John Dewar Phillips Trust Alwyn Werrell

#### Friends of the Institute

Adinfern Estate Albrecht Fear Real Estate Alder Tapware Atomer Mining Auto Classic Barnett's Architectural Hardware

Betts & Betts/Zu BM & Y Breakaway Resources Brown Hill Cape Mentelle Clipsal Australia Consortium Builders Pty Ltd Cottesloe Golf Club Cowaramup Primary School CSA Australia Pty Ltd Daily Living Products Dawsons Garden World Doug Buckey Carpet Court Drummond Golf Steve Duggan Phil Dyer Neil Earl Elphick O'Sullivan Fremantle Furniture Chris Gannon Hartway Galvinisers Hawaiian Management Group Hampton Hill Mining John Hughes Hungry Jacks Hunt & Humphry Innerspace Commercial Interiors Intermedia Productions Val Jasper JWH Group KPMG Lane & Mitchel Brad Logan Mack Hall & Associates Real Estate Gary & Lynley Madson Margaret River Arts Council Margaret River Bakery Margaret River Farm Fresh Eggs Margaret River Pharmacy Members Equity Bank Merit Projects Millbrook Winery Minara Resources Minot Wines Monarch Gold Mining Montagu Stockbrokers Jenni Montgomery Mundella Foods Niagara Mining Ltd Oakwood Funerals Oldfield Knott Architects Palandri Wines Paxton Hoad Paxton Hoad West Philip Griffiths Architects Jean Pryor Potter Cook & Dodd Real Estate Redgate Wines Rokeby Dental Services Rosabrook Wines Shellabears Real Estate Steelmet Stella Bella Summit Homes Group Sunscape Industrial Relations & Management Consultants Super Signs Teck Cominco Australia Pty Ltd Mrs Treloar WA Sports Centre Trust Watershed Wines Westfuel

Julie Wheatley Whelans Willfish Wills Domain F Witting Chip Yelverton Ye 'ole Lolly Shoppe

#### The Meningitis Centre

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### Passionate people Dr Eve Blair



Eve Blair's dream is to reduce the incidence of cerebral palsy.

For the past 26 years she has been part of the Institute, working closely with Fiona Stanley in the area of cerebral palsy research.

Eve leads a small research team that maintains the WA Cerebral Palsy Register, one of the longest-standing cerebral palsy registers in the world.

"We are interested in understanding the pathways to cerebral palsy with the aim of identifying points at which they may be interrupted effectively and acceptably," Eve says.

"We also want to develop better management strategies for children with cerebral palsy."

One of the major findings of the Institute's research into cerebral palsy was the realisation that birth asphyxia was not responsible for the majority of cases of cerebral palsy. "This finding had major implications for litigation claims against obstetricians," says Eve.

Eve came to the Institute with a background in chemistry. However, when she moved to Western Australia, she made the decision to study medicine more closely.

"I was introduced to Fiona Stanley and after working as her research assistant, I decided that I needed some more appropriate qualifications so obtained a PhD in medical science."

Eve has since become an expert in cerebral palsy research. She wants to develop a reliable, Australiawide method of describing the clinical symptoms of cerebral palsy and hopes to see the Australian Cerebral Palsy Register fully-funded, operational and using this reliable method of description.

With physiotherapist Sarah Love, she also hopes to identify whether

early Botulinum toxin A therapy can establish a normal gait pattern in children with mild to moderate cerebral palsy, avoiding the need for later rehabilitation.

Eve's research career has produced many highlights. A major one says Eve, was completing a cerebral palsy research book in 2000 with Professors Eva Alberman and Fiona Stanley.

"The book allowed me to describe my research of the previous 18 years in greater detail than is possible in peer-reviewed papers," she says.

Eve hopes that her research findings will help obtain adequate federal support for those with cerebral palsy on a needs basis.

"I'm a strong campaigner for a fairer deal for children with cerebral palsy."

"The real drivers of my research are to make life more rewarding and to spread resources more efficiently."

## Every child should feel hope.



# Every one of us can make a difference to the life of **every child**.

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

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100 Roberts Road, Subiaco Western Australia 6008 PO Box 855, West Perth Western Australia 6872 Telephone 08 9489 7777 Facsimile 08 9489 7700 Email enquire@ichr.uwa.edu.au www.ichr.uwa.edu.au

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This Annual Report was produced by the Public Relations Office of the Telethon Institute for Child Health Research. Published in May 2007. Project management, copywriting/editing and design - Tammy Gibbs. "Every Child" creative concept and copywriting - Elizabeth Chester: We wish to acknowledge the staff of the Telethon Institute for Child Health Research for their contributions to the 2006 Annual Report. Printing - Abbott & Co. 08 9353 1166.