imagine....

PREVENTION
INNOVATION
DEDICATION

TELETHON INSTITUTE FOR Child Health Research

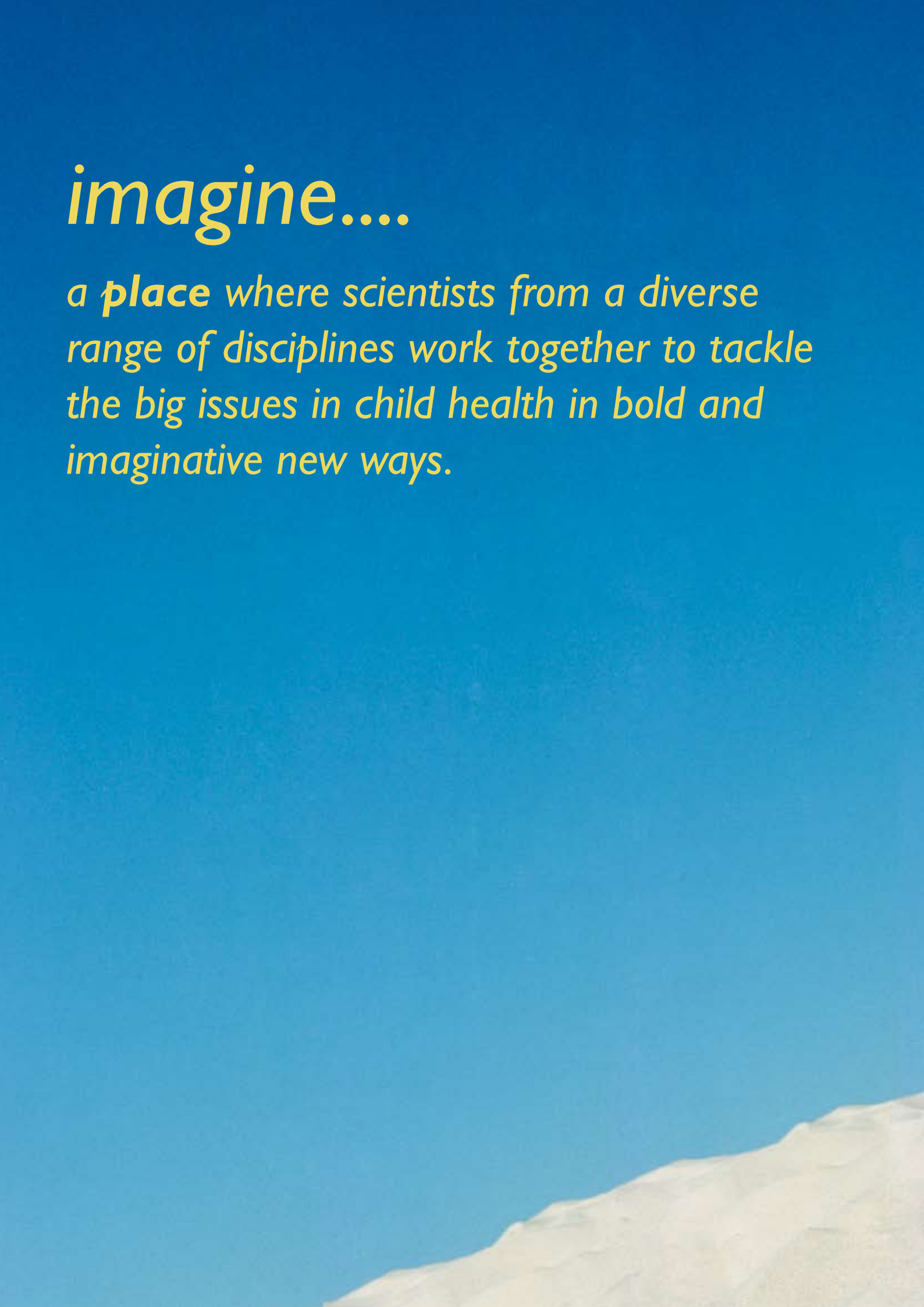
Annual Report **2005**

imagine....

a ***time*** *where children are free to relish the joys of childhood, free from diseases, disabilities and disadvantage.*

imagine....

*a **place** where scientists from a diverse range of disciplines work together to tackle the big issues in child health in bold and imaginative new ways.*



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 outskirts of the Perth CBD and have close to 400 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

imagine....

*if **every child** was given the chance to be all that they can be.*

The fact is that many children begin life with the odds already against them.

Some face chronic, debilitating or life-threatening diseases.

Others are born with disabilities that present a life-long challenge to them, and to their families.

An increasing number battle profound economic and social disadvantage as the disparity between the haves, and the have-nots, increases.

Why is it, at a time of increasing technology and affluence, many of the key indicators reflecting the health and wellbeing of children are either static or getting worse?

Why is it that mental health problems such as ADHD, eating disorders, youth suicide and risk-taking behaviours are increasing?

Why are we seeing such high rates of pre-term births, diabetes, asthma, autism and cerebral palsy?

We don't, for a minute, **imagine** that the answers to these questions will be simple.

But we do know that we won't find the answers unless we apply our scientific rigour in new ways.

That's why our Institute brings together hundreds of researchers from a diverse range of different scientific disciplines to tackle the big issues in child health in bold and imaginative new ways.

From the realms of imagination into reality – the Telethon Institute for Child Health Research.

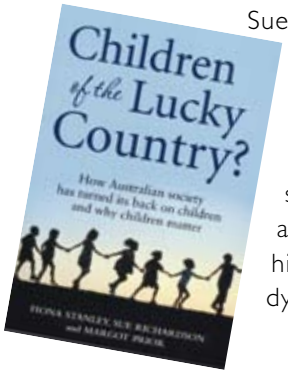
PREVENTION INNOVATION DEDICATION

Highlights for 2005

2005 was another great year for the Telethon Institute for Child Health Research. We share with you our highlights for the year.

- Our total research income for the year was $18.7 million.
- Our researchers presented their research findings far and wide, from Melbourne to Munich, Sydney to San Antonio, Kalgoorlie to Kuala Lumpur.

- In 2005, our researchers published extensively with 138 publications including research papers in national and international journals, books, book chapters, reports and special newsletters.
- We obtained funding from the Western Australian Centres of Excellence in Science and Innovation Program to purchase a high-speed cell sorter, and increase our bioinformatics capacity through two new staff appointments over the coming five years.
- Board member Mr Harvey Coates was honoured in the Australia Day awards, becoming an Officer of the Order of Australia (AO).
- Our Board of Directors welcomed Mr John Langoulant, Chief Executive of the Chamber of Commerce and Industry of WA, and Mrs Jenni Ker as the new President of the Friends of the Institute. Jenni took over from Mrs Marilyn Stewart who was farewelled in 2005.
- Our Director Professor Fiona Stanley wrote a book, *Children of the Lucky Country?* with Professors Sue Richardson and Margot Prior. The book looks at the state of children and families in Australia today and analyses what is happening to explain our current situation. Australia has an astonishing level of affluence, but high levels of social disparities and dysfunction in spite of this wealth.



- We were designated a World Health Organization (WHO) Collaborating Centre for Children's Environmental Health Research, the only WHO collaborating centre of its kind in Australia with a focus on environmental health in children.
- Our first spin-off company, Phylogica Ltd, was publicly listed on the Australian Stock Exchange. Phylogica has made a number of announcements in relation to its Phylomer® technology, particularly in the areas of stroke, rheumatoid arthritis and burns.
- In May, a crowd of more than 700 gathered at the Perth Convention Exhibition Centre to hear a panel of prominent leaders spearhead a debate on the social and business issues facing WA. John Rothwell, Fiona Stanley, Len Buckeridge, Jack Bendat and John Poynton led the discussion which was facilitated by respected journalist Maxine McKew. The event was presented by Ernst & Young and The West Australian as a fundraiser for the Telethon Institute.
- Our asthma research team finalised arrangements for a world-first international research trial into a treatment that could prevent asthma in high-risk children. The treatment, developed by Institute 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. *(see page 16)*
- A groundbreaking new project to tackle the specific challenges in Indigenous child health was awarded an Indigenous health research capacity building grant from the National Health and Medical Research Council (NHMRC). The five-year grant was awarded jointly to the Telethon Institute and Curtin University of Technology. This is the first NHMRC capacity building grant comprising all Indigenous team investigators.
- Our cancer research team identified crucial genes in a range of common cancers that have been reported to predict a patient's response to treatment. By using a simple test, the presence or absence of tumor suppressor genes can be rapidly detected in the patient's cancer cells, helping to determine who is at greater risk of relapse. This is an important milestone towards more individually targeted and effective treatments for cancer patients. *(see page 18)*

We released the community results of the Australian Early Development Index (AEDI), a national research project that measures children's developmental progress as they enter school. Nearly a quarter of Australian children could be developmentally at risk, according to the findings of more than 16,700 children from 25 communities across Australia. Pictured below, Senator Kay Patterson celebrates the release of the AEDI results with a youngster in Victoria. *(see page 26)*

We launched Volume Two of findings from the Western Australian Aboriginal Child Health Survey. The landmark report on the social and emotional wellbeing of Aboriginal children, found that nearly a quarter (24 per cent) of Aboriginal children are at high risk of clinically significant emotional or behavioural difficulties (compared with 15 per cent in the general population). The survey details the complexity of factors that contribute to significantly higher rates of social and emotional difficulties experienced by Aboriginal children compared with other Australian children. *(see page 14)*

We launched several new vaccine trials including an influenza vaccine for children and a new combined vaccine to protect against three types of potentially deadly bacterial meningitis. *(see page 22)*

Ministerial Council for Suicide Prevention researcher Kate Miller was recognised for her innovative work in developing safe, effective online resources for young people. She was awarded a LiFe Award by Suicide Prevention Australia. Kate developed a unique Internet resource targeted at young people who access suicide prevention information or support through the Internet. Professor Sven Silburn, Chair of the Council at the Institute, also received an Outstanding Contribution Award to acknowledge his major role in suicide prevention research in Australia. *(see page 24)*

We published the results of the first large-scale scientific evaluation of group-based positive parenting programs and found that they reduce clinically significant behavioural problems in children by 36 per cent. The results showed that positive parenting programs are effective and can be offered on a widespread and cost effective basis through child and community health services. *(see page 24)*

A team of Perth scientists from the Telethon Institute, the Western Australian Institute for Medical Research and PathWest, combined to help a Queensland couple solve the mystery of their 7-year-old daughter's death – 14 years after she died. Researchers established that the little girl died from the devastating neurological disorder Rett Syndrome, and made the diagnosis after carrying out a gene test on DNA extracted from a keepsake baby tooth. *(see page 28)*

We conducted a comprehensive review of scientific studies on the use of baby pacifiers (dummies) and found that they interfere with successful breastfeeding. Repeated studies have found that dummies result in a reduction of breastfeeding duration or exclusivity. *(see page 26)*

We received an ARC Linkage Grant to look at developmental pathways to health, education and delinquency outcomes in Western Australian children. The project will use an holistic approach to inform early intervention strategies to enhance wellbeing and life chances. The project is the first in Australia to bring together data across multiple disciplines and government sectors. *(see page 20)*

Our Kulunga Research Network welcomed Troy Cook as the new Patron. Troy, who plays football for the Fremantle Dockers, will help the Network to get key messages out to the Aboriginal communities of Western Australia. Pictured below, Troy celebrates his new role with some young fans.

Chairman's message

At the final Board meeting for the year 2005, it was with some pride that Board members reflected on the achievements of the Institute over the past twelve months and indeed since operations commenced some sixteen years ago.

In so doing, the Board was very much aware of the need to address the major changes now looming at national and state level. These will have a significant impact on child health and medical research, and therefore on this Institute.

With gross income for the year exceeding $25 million, and research income exceeding $18 million, the Institute has a sound base from which to support the on-going success of the research teams.

The challenge for the Board is to ensure the required funding and facilities meet future needs and growth. Particular needs relate to strategic recruitment, the ever-increasing cost of technology and research equipment, and future building demands.

The Commonwealth Government has announced that by 2007 it will be engaging in a Research Quality Framework (RQF) assessment exercise for all Australian universities. Essentially, the Government will be applying processes and measures to assess the quality and impact of research in Australia's universities and publicly-funded research agencies. This will add an extra dimension to the value of our relationships with universities.

At State Government level, the Institute has been actively involved in the implementation of the health reform agenda, which is being coordinated through the Health Review Implementation Taskforce. Given the close working relationship between the Institute and Princess Margaret Hospital for Children (PMH), the Board is now examining the impact on the Institute of a future relocation of PMH. This is part of the Metropolitan Health Services Plan. The Board has already commenced the long-term planning involved in such a major undertaking, the funding requirements for a new building and the possible sources of funding, including the commitment already from the State Government.

As the Government plans unfold, as Board Chairman I shall be very much involved in engaging with my counterparts and fellow Board members in other medical research institutes in Western Australia, in working together to present our common interest. The cost-benefit of medical research, to the state and to the public, has been well documented and I know that we are all committed to this important advocacy role.

It is timely that the next international five-yearly review of the Institute, our next quinquennial review, will be taking place in November 2006.

Preparations for this review commenced during 2005 and are now well advanced. The Chairman of the review panel is Professor Don Roberton, from the University of Otago (NZ). The focus of the review will be wide-ranging and will include the quality and effectiveness of our research programs, and the relevance of our current mission and aims. The panel will also comment on plans for the future location of the Institute.

During 2005 the Board initiated

two significant exercises in the pursuit of effective governance. With the assistance of Mr Richard Thomas, a partner of Deloitte in Perth, and consistent with the guidelines from Standards Australia, the Institute engaged in preparing a risk analysis and risk management profile. While this is a continuing exercise and one involving the senior staff, the Board is committed to the concept of risk management as part of the strategic planning process.

The other initiative has been the preparation of a Corporate Governance Manual. Solicitors Blakiston and Crabb volunteered their services to prepare a Corporate Governance Manual for the Institute. The exercise was duly undertaken and the final documents were presented to the Institute in November. These documents have been subsequently adopted by the Board as working documents and for future reference.

I would like to acknowledge the work of the officers from both Deloitte and Blakiston and Crabb respectively for their contributions to the better management of risk and the better governance of the Institute.

Another milestone for the Institute was achieved in 2005 with the public listing of Phylogica, the first of our commercial spin-off companies to be publicly listed. My congratulations to all of those concerned.

In concluding this report may I acknowledge the importance to the Institute of our many stakeholders and supporters.

The support of our donors helps us grow our capital fund, which provides the Institute with the capacity to plan for the future and implement strategic initiatives to enhance the effectiveness of our research. This includes developing our younger scientists to be future leaders in their field, underpinning the funding in key areas of research and having the ability to attract new and retain existing eminent researchers.

Existing sources of research and research support funding do not normally provide for such initiatives. Therefore, it is our aim to build our capital base to a level where the annual income it generates will enable us to plan with confidence and implement sustainable programs.

The capital fund currently stands at $17 million and we aim to reach our target of $30 million over the next three to five years. To achieve this aim, Telethon is vital and we are particularly grateful to Channel 7 and the people of Western Australia for their continued support. We are indebted to other major donors including: Stan and Jean Perron, Wesfarmers, Rio Tinto, QANTAS, Shell and Alcoa and to the many businesses, schools, families and individuals who support us.

I would also like to acknowledge the support of the Commonwealth Government and the Government of Western Australia for the various funding programs that support child health and medical research and therefore the work of this Institute.

The Friends of the Institute are now well established, including the newly-incorporated branch in Margaret River. Both Perth based and Margaret River Friends have again made an extraordinary contribution to the work of the Institute through both fundraising and "friend raising" on our behalf.

Many thanks to our long-serving honorary auditors, KPMG, for their services again this year.

Finally may I thank my fellow Board members for their commitment, diligence, and wisdom in the exercise of good governance and for their passion for the wellbeing of the Institute and what it represents.

Congratulations and continuing best wishes to Professor Fiona Stanley and to her outstanding team of staff and students who undertake such important work "to improve and to promote the health and wellbeing of all children through the unique application of multidisciplinary research".

Kevin Campbell AM
Chairman of the Board

Director's Report

To me, the theme of this year's report couldn't be more timely. The past year has shown us the power of taking imaginative ideas and transforming them into reality. It has also reinforced to us that without an imaginative new approach, then some of the major dilemmas affecting the health and wellbeing of children are unlikely to be resolved.

When you're looking at how imaginative ideas can lead to wonderful solutions, it's hard to look past the endeavours of Western Australia's Nobel Prize winning scientists, Barry Marshall and Robin Warren. It's a combination of their imagination, dedication and, at times, unconventional approach, that has seen them awarded their well deserved accolade for discovering the cause of gastric ulcers. There is an adage "if we always do what we've always done, then we'll always get what we've always got." While a rigorous scientific approach should never be compromised, it is becoming increasingly apparent to us at the Institute that we have to look more broadly than we have done before and work in collaborative new ways if we are going to *really* tackle child health and wellbeing. That means working with education, the community, justice, economics and the environment, to explain the rise in complex diseases that we're now experiencing.

It's also why we need an increased commitment to fund high quality research if there is to be any relief on overburdened public health systems. Focusing on emergency rooms and waiting lists, and continually increasing "sickness" budgets will never improve health and is simply not sustainable. At some stage, we have to make a commitment to improving the health of the population with preventative strategies. We already know how effective these can be – vaccination and anti-smoking campaigns for example. "An ounce of prevention is worth a pound of cure" and we also know that many of the pathways to good health begin in childhood. However we continue to be concerned that amid the focus on critical care, population health is not getting the priority it deserves.

For our Institute, we are particularly well placed to undertake this type of broad, holistic research into what makes a healthy society. This Institute was founded on an imaginative concept – what would happen if we could bring together laboratory and clinical scientists with epidemiologists? I'm proud to say that this collaborative approach is now starting to reap the dividends.

It's particularly driving one of our major research grants received in 2005 where the Institute is leading a consortium of researchers that includes the Crime Research Centre at the University of WA and several State Government departments: Community Development, Education and Training, Health, and Justice, together with the Office for Children and Youth and the Disability Services Commission. Funded by the Australian Research Council, the $1.3M project is looking at developmental pathways to health, education and delinquency outcomes in Western Australia children, and is adopting a holistic approach to inform early intervention strategies.

This year the State Government recognised the high quality of research in asthma and

allergy, and children's cancer and leukaemia, at the Institute with a grant of $1.7M in May to establish our UWA Centre for Child Health Research as a Centre of Excellence. The Institute was also a major partner in the establishment of Data Linkage Australia as a Centre of excellence under the same Program.

Other successes in 2005 included the public listing of the Institute's first spin-out company Phylogica which is developing new drugs for stroke and other inflammatory diseases based on Institute research led by Dr Paul Watt. The year also saw the launch of the second volume of the WA Aboriginal Child Health Survey – a landmark report on the social and emotional wellbeing of Aboriginal children and their families. The findings are quite confronting and provide powerful data to inform policy in this critically important area. Volume three on Education will be released in 2006.

Of course much of our research relies on the support of others who share our vision.

We have received enormous support from both corporate – Telethon, Wesfarmers, Shell, Rio Tinto, Alcoa, Qantas, KPMG, Ernst and Young, Woodside -- and individual philanthropists. This year saw the start of a five year program of support for early career researchers made possible with major support from the Stan Perron Charitable Trust. Two PhD students were given Stan and Jean Perron Awards, which are designed to attract outstanding postgraduate students to the Institute to undertake research.

The Institute was very honoured to host in February 2005 a great pioneer in epidemiological and population health research, Sir Richard Doll. His best known research on smoking linked it to many diseases including lung cancer, emphysema, and heart attack. Sir Richard met with researchers supported by the NHMRC's Indigenous Capacity Building Grant to Aboriginal researchers at Curtin University, the Institute, and the University of WA. We were deeply saddened to learn of Sir Richard's death in July, aged 92.

In 2005, we were also very honoured that inspirational Aboriginal leader Mandawuy Yunnupingu agreed to become a Patron of our Institute. We also congratulate Board member Harvey Coates who was made an Officer of the Order of Australia (AO) in the Australia Day Honours.

The year ahead will see an every greater effort to engage sectors outside of health in helping us to understand what it takes to build a healthy society for our children. We are also taking a leading role in developing new models of consumer and community participation, led by Anne McKenzie. And we have another major issue to consider – the possible relocation of the Institute as the Government looks to move Princess Margaret Hospital. We are working closely with clinicians, policy makers and other research facilities to ensure we remain well positioned to undertake our work.

My personal thanks go to our outstanding Board for their dedication and commitment and to all the staff who have contributed so much to make 2005 such a successful year.

Fiona Stanley AC
Director

Aboriginal researchers Dr Cheryl Kickett-Tucker, Associate Professor Ted Wilkes, Dr Helen Milroy, Dr Janet Hammill, Dawn Bessarab, Daniel McAullay and Juli Coffin with Sir Richard Doll (seated front).

imagine....

What could be better than effective treatments or even a cure?

PREVENTING disease, disability and disadvantage **BEFORE** it occurs.

We've set our sights high, but our focus on prevention is already paying dividends.

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

imagine....

If Aboriginal children were given the same chance in life as other Australians kids.

From even before they're born, Aboriginal children face greater hurdles than most other Australian children. They are more likely to be born pre-term and with a lower birth weight. The rates of SIDS remain alarmingly high in Indigenous communities. As children, they suffer a great burden of infectious disease and emotional and behavioural problems.

The Institute's ground-breaking Western Australian Aboriginal Child Health Survey is the most comprehensive analysis ever undertaken of the complex range of factors affecting children's health and wellbeing. In partnership with Aboriginal people, the Institute's Kulunga Research Network is pioneering preventive strategies to improve outcomes for children. Kulunga has brought together an outstanding team of Aboriginal researchers to work on issues ranging from fetal alcohol syndrome to Indigenous self-esteem.

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
Western Australian Aboriginal Child Health Survey	A survey of Aboriginal children aged zero 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.
Swimming pools project	Swimming pools were built in three remote Aboriginal communities in Western Australia in 2000. Our research team has been following children in two of these communities - Jigalong and Burringurrah - to assess the effect of the swimming pool on their skin and ear health.	The study began in May 1999. Communities have been visited every six months, during summer and winter. Communities adopted a "no school, no pool" policy. The project concludes in early 2006.
Rio Tinto Child Health Partnership	Developed to deliver improvements in Aboriginal and Torres Strait Islander child and maternal health. Aims to achieve this through the delivery of three projects: • modelling the WA Aboriginal Child Health Survey for the NT and QLD • national fetal alcohol syndrome prevention strategy • enhancing Aboriginal workforce capacity.	Partners include: • Rio Tinto • Alcohol Education and Rehabilitation Foundation Limited • Western Australian government • Northern Territory government • Queensland government • Telethon Institute for Child Health Research

Detailed information about our research may be found at our website at www.ichr.uwa.edu.au

Our research

In April 2005, the second volume of findings on the social and emotional wellbeing of Aboriginal children and young people was launched.

Key findings from Volume Two show that:

- nearly a quarter (24 per cent) of Aboriginal children are at high risk of clinically significant emotional or behavioural difficulties, compared with an equivalent figure of 15 per cent in the general population. These difficulties include problems with emotions, feelings and behaviours, episodes of self-harm or attempted suicide, cultural and spiritual engagement and family experiences of loss, grief or trauma.
- over two-thirds (70 per cent) of Aboriginal children were living in families which had experienced three or more such life stress events. 22 per cent of Aboriginal children had experienced seven or more of these serious events in the past 12 months. For most children, one major life stress event such as a death in the family, serious illness, family breakdown, financial problems or arrest would be overwhelming.
- one quarter of Aboriginal children (25 per cent) were living in families with poor quality parenting. These children were almost four times as likely to be at high risk of clinically significant emotional or behavioural difficulties than Aboriginal children living in families with very good quality of parenting.
- about one third (34 per cent) were in the care of a sole parent. These children were twice as likely to be at high risk of clinically significant emotional or behavioural difficulties than children cared for by both original parents.
- the effects of the Stolen Generation are present today with children of Aboriginal carers who were forcibly separated from their families being 2.3 times more likely to be high risk for clinically significant emotional and behavioural difficulties and with double the proportion of both alcohol and other drug use than other Aboriginal children.
- of Aboriginal young people aged between 12 and 17 years, 35 per cent have smoked regularly, 27 per cent drink alcohol (compared with 18 per cent of non-Aboriginal teenagers), 30 per cent had used marijuana, 19 per cent had been in a car with a drunk driver in the six months prior to the survey, and 16 per cent had seriously thought about ending their own life in the 12 months prior to the survey.

When compared with pre-pool rates, data from the period 2001 to 2005 at the Jigalong community shows that there have been reductions of:

- 41 per cent in antibiotic prescriptions
- 44 per cent in ear disease
- 51 per cent in skin disease. Skin sores are associated with rheumatic heart disease and kidney disease.
- 63 per cent in respiratory disease.

The pools have also boosted self-esteem, improved school attendance and improved the confidence of the children around water.

In 2005, achievements of the Partnerships include:

- Successful modelling of the WA Aboriginal Child Health Survey (WAACHS) data for Queensland and the Northern Territory
- Agreement by the Australian Health Ministers Advisory Council to consider modelling the WAACHS in other states
- All three States taking the lead on managing the different projects whilst maintaining regular communication to align, support and inform local community-level implementation
- The development of a communication strategy including the publication of the Partnerships first newsletter
- Agreement to host a national symposium on promoting health pregnancy in Indigenous communities
- Notable developments in a number of the sites.

imagine....

A vaccine to prevent allergies and asthma.

For the past 15 years, our world-leading asthma and allergy scientists have been tracking the pathways that lead to chronic asthma. Their work has helped to identify how a child's immune system is programmed and which children are most likely to develop asthma. Now, that knowledge has led them to test a new vaccine that could prevent asthma and allergies in high-risk children.

Asthma, allergies & 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 causes normal mucus in the lungs to become thick and sticky. This mucus clogs the tiny passages in the lungs and traps bacteria. Repeated infections and blockages can cause irreversible lung damage and death.	Cystic fibrosis is the most common serious inherited condition in Australian children, with around one in every 25 people carrying the cystic fibrosis gene. Around one in every 2,000 babies born in Western Australia will have cystic fibrosis. There is no known cure.
Allergy	An allergy is an exaggerated response to a substance that is normally considered harmless. This exaggerated response could be due to a reaction to food or food additives, to pollutants in the air outside or in the home, to chemicals in our surroundings where we live or work or in the many everyday items we use.	Common allergens in children include grass pollen, house dust mite, dander from cats and dogs, feathers and certain foods. The incidence of food allergies has doubled in the past decade. The most common food allergies in children are peanuts, tree nuts, milk, egg, soy, sesame, shellfish and fish.

Detailed information about our research may be found at our website at www.ichr.uwa.edu.au

Our research

We are very excited to be leading a world-first international trial of an asthma vaccine. For three years, we have been planning the trial which aims to prevent allergy, and therefore asthma, in high-risk children. The trial involves giving children drops of common allergens (house dust mite, cat and grass) under the tongue to try to educate their immune system to not over-react to these allergens. The trial will commence in March 2006 with the recruitment of 200 high-risk children aged between 18 and 30 months from Perth, Melbourne, New York, Stockholm and Berlin.

House dust mites continue to be a major trigger of asthma in Western Australia. An immune response occurs following exposure to a complex mixture of proteins found in the waste products of mites. We have been looking at both the highly-allergenic and poorly or non-allergenic proteins as well as the differences in responses of severely and mildly allergic people.

During 2005, we continued to collect information on 1,500 13-year-old children from the Raine Study with the aim of identifying features that predispose to allergy and asthma. We are examining the clinical history, genetic profile, lung physiology and immunology of the teenagers. We hope the information collected on asthma will help identify biomarkers for the various asthma subgroups to assist in the diagnosis, prognosis and treatment choice for children with asthma and allergy.

Epidemiological studies have found associations between stress in early life and allergic diseases such as asthma. We have developed a carbon dioxide inhalation test to assess stress responsiveness in children. The test is very well tolerated and results in a significant increase in salivary cortisol levels. More than 1,470 teenagers from the Raine Study have been assessed using this test. Preliminary results show associations between anxiety and stress responsiveness with some gender differences being identified. Data collection will be completed in 2006 with early life factors and the asthma and allergic status of the individual forming part of the results.

During 2005, we continued to look at the early development of inflammation and infection in children with cystic fibrosis. We have collected more than 330 lung fluid samples from 100 children with cystic fibrosis. Inflammation was evident in all samples and shows us that once acquired, inflammation occurs side-by-side with infection.

The role of inflammation is to attack invading pathogens 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. It is this collateral damage from inflammation and infection that initiates fibrotic lesions, 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 trialed nationally and internationally in people with the disease, will help reduce levels of lung damage.

We have also been looking at a class of antibiotics (known as macrolides) to see if they can reduce inflammation and improve lung function of patients with cystic fibrosis, when used with regular therapies.

Our immune system protects us from the outside world. However, sometimes it can become overprotective, launching a full-blown attack on one of those harmless substances that previously would have provoked little or no response. Many allergic reactions are mild and limited to localised hives or swelling. Serious allergies can cause anaphylactic shock, a sudden, aggressive and potentially life-threatening allergic reaction.

We are studying allergic responses to peanuts. Peanut allergy is important because peanuts often produce severe and life threatening or fatal immediate reactions. Their risk to health is compounded by the use of peanuts as a "filler" ingredient in a wide variety of foods. The responses of peanut-allergic subjects to the major peanut allergen (Ara h 2) are being studied by gene expression analysis. This research is important for the food industry and the severe nature of the response may help uncover basic molecular mechanisms of sensitisation.

Our research into cat allergens has concentrated on the proteins detected in cat dander and cat skin. We have also been looking at saliva and other gland secretions which are known to play an important part in cat allergy.

imagine....

Individually tailored treatments to improve the survival of children with cancer.

Leukaemia is the most common cancer affecting children. Advances in treatment now means that the prospects for children with this devastating disease are much more positive. But despite the improved survival rate, around 20% of children relapse. Our internationally recognised researchers have developed a test that finds genetic markers which indicate those children who are most at risk of relapse so that their cancer can be treated more aggressively to give them the best chance of recovery.

Cancer

	About	Facts and stats
Leukaemia	Leukaemia is cancer of the white blood cells and these white blood cells are produced in the bone marrow. Our leukaemia research Division is a member of the US-based Children's Oncology Group, the world's largest study group into childhood cancers.	Leukaemia is the most common form of cancer in children, accounting for around one third of all cases. Leukaemia affects around one in every 2,000 children in Australia. It is more common in boys than girls with a 1.4 to 1 ratio. There is a peak incidence in children aged between two and four years. Survival rates have increased to more than 70 per cent.
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.

Detailed information about our research may be found at our website at www.ichr.uwa.edu.au

Our research

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.

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.

In previous research, we successfully identified a tumor suppressor gene associated with acute lymphoblastic leukaemia (ALL) in children. In 2005, we applied this knowledge to a range of common cancers and identified crucial genes in these cancers that predict a patient's response to treatment. This discovery resulted in the development of a simple test that can rapidly detect the presence or absence of these tumor suppressor genes in the patient's cancer cells. The test provides valuable genetic information that will help doctors tailor treatments for individual patients who may have been diagnosed with cancers such as lung, breast, renal, pancreatic and gastric carcinomas, lymphoma and malignant melanoma.

2005 saw the completion of the third year of a five-year study 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. During the year, we continued to recruit study participants with the aim of including 350 children newly-diagnosed with ALL and 700 children without leukaemia. With the assistance of paediatric oncology centres around Australia, 250 children who have achieved remission have consented to take part in the study and will complete questionnaires and provide DNA samples. 521 families of children without leukaemia have completed food questionnaires and 344 have provided DNA samples.

PNETs are an aggressive type of tumour and a significant proportion of patients do not survive. Many survivors face serious post-treatment quality of life issues, a result of brain surgery and chemotherapy or radiotherapy.

The molecular biology of PNETs is not only complex, but also poorly understood. Our brain tumour research program aims to increase knowledge of the disease so that safer and more effective drugs and treatments can be developed to improve outcomes for PNET patients.

Chromosomal abnormalities are a common feature of PNET cells, including rearrangements, duplications, deletions and amplifications. This shows the complex nature of PNETs and suggest that multiple genes are involved in the brain tumour's development. During 2005, we identified several genes of interest in PNET cell lines - some of these genes have not been previously linked to brain tumours and provide promising new leads for future research.

We have also just begun a three-year study to examine the effects of genetic and environmental risk factors of childhood brain tumours. In 2006, the study will begin recruiting 350 children with brain tumours. In 2007, 300 control families will be recruited.

The ultraviolet rays in sunlight not only cause sunburn, they can also suppress the immune system. We know that the same UV rays can turn a normal skin cell into a cancerous one, and this effect on the immune system can result in the 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. We are therefore identifying the critical events initiated in the outermost layer of skin. One target is a relatively innocuous chemical in the skin - "urocanic acid". On exposure to UV rays it changes its structure, and it can now affect immune responses. Also, some cells in the skin are stimulated to release other chemicals which affect immunity. Currently we are identifying the changes that are made to cells of the immune system initiated by those critical early events.

Whilst our research has shown that these changes in immunity might be more important for melanoma and basal cell carcinoma, all skin cancers are likely to be affected. We are studying the way in which UV rays affect immunity to see whether we might not only find ways of treating or preventing skin cancer, but also be able to apply that knowledge to prevention or treatment of other diseases involving the immune system, such as some skin, lung and autoimmune diseases.

imagine....

What you'd learn by watching thousands of children grow from the womb to their teens.

That's exactly what we're doing with our world-renowned Raine Study. Our researchers have tracked more than 2,500 children for the past sixteen years, from their mother's pregnancy, through early childhood, adolescence and now their teenage years. It's just one of a number of long term studies at the Institute that are expanding our knowledge about what children need for healthy development.

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 Raine Study is a multi-faceted collection of data regarding a broad range of aspects of child health and development.	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 researchers from the Institute, the School of Women and Infants Health at the University of Western Australia, Curtin University of Technology and the University of Notre Dame who are working together to study a number of important health and developmental processes that have the potential to influence health and wellbeing throughout life.
Childhood obesity	Childhood obesity is a major health problem which can continue into adulthood. Childhood obesity 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.	Australian-wide data suggests that 19 to 23 per cent of Australian school children are either overweight or obese.
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 with language.	SLI currently affects approximately seven per cent of WA single-born children with otherwise normal development. The rate of SLI in twins is not known.
ARC Linkage Project	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.

Detailed information about our research may be found at our website at www.ichr.uwa.edu.au

Our research

In 2005, we continued assessments with the more than 1,600 teenagers involved in the 13-year follow-up. This follow-up has collected information on physical activity, physical fitness, motor competence, nutrition, posture, joint mobility, back muscle strength, blood pressure, respiratory function, allergy, and stress responsiveness. We are also interested in child and adolescent mental health and family functioning, general health, and school achievement, and blood was collected for analyses that relate to our interest in allergic conditions and the early development of metabolic disturbances.

Data collected to date suggests that almost half of the Raine teens assessed have experienced back pain and that this may be caused by posture and patterns of movement whilst using computers for homework, internet searching or playing games.

The information we have collected on nutrition suggests that teenagers aren't eating the recommended two serves of fish per week, that more white bread is consumed and not enough wholegrain or wholemeal breads, and that many teens have diets high in snack foods like chocolates, lollies, potato chips and soft drinks.

In 2005, consumer and community participation became an important new focus for the Raine Study with teens, parents and carers taking part in a workshop to discuss how they would like to be involved in the management of the study. As a result, a youth group has been established, providing a forum for study participants to have input into how the study is run.

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

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.

At the end of 2005, more than 1,200 children from different areas of metropolitan Perth are taking part in this research. We have interviewed 347 of these children and 247 parents. More than 200 children have come back for their one-year assessment with some families progressing to their 18-month assessment. We will continue to follow-up the families involved in this study for at least three years.

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 during their toddler, preschool and school years.

During 2005 we continued to recruit twins and single-born children to the study and to date have 702 twin pairs and 237 single-born children enrolled. We have also assessed 404 family members of children at risk for language acquisition.

We use questionnaires to find out about language development and the factors in the lives of children and families that influence how they are growing up, and face-to-face assessments involving new techniques such as the use of puppets to assess grammatical development. The obtained data subdivides into two general types - direct behavioural assessments of language and cognition, and questionnaire data of child, maternal, and family variables. The protocols for language and cognitive assessment are age-adjusted to match the child-to-adult range for families as well as the target twins and singletons.

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 and wellbeing and competence among our children and youth are critical human resources upon which future economic prosperity will depend.

This project got underway in 2005 with the development of the PhD research projects, establishment of a communication and consumer group and the commencement of the coordination of the various data and information sets held by the partner government departments.

imagine....

If we could protect children from deadly and debilitating infections.

Vaccinations may now seem routine, but infectious diseases are still the most common cause of death in children. Our research teams are evaluating new vaccines for a range of common diseases. We're also investigating how viruses cause disease within the central nervous system, focusing on the increasing scourge of encephalitis and enterovirus. More common infections such as otitis media (glue ear) can cause life-long problems by seriously impairing speech and hearing, schooling and subsequent wellbeing.

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 the pneumococcus and meningococcus and in newborns, group B streptococcus. Viral meningitis is more common than bacterial meningitis and is usually an uncommon complication of some common viral illnesses such as measles, mumps and chicken pox. Fungal meningitis is a very rare, life-threatening disease and may be caused by a variety of fungi.
Pneumococcal disease	The pneumococcus is a bacterium (also called *Streptococcus pneumoniae*) that causes meningitis, pneumonia (inflammation in the lungs), septicaemia (blood poisoning) and severe ear infections. The pneumococcus is often carried in the upper respiratory tract and the back of the nose and throat of healthy children and adults. The bacteria are spread from person-to-person through inhaling droplets and through close personal contact. 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 2005, there were 138 reported cases of invasive pneumococcal disease and 21 deaths in WA. With the introduction of universal infant pneumococcal vaccination, the number of cases in children under five years of age fell from 49 in 2004 to 21 in 2005.
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.
Enterovirus 71	Enterovirus 71 is a gastrointestinal virus that can cause paralysis in toddlers. The most common symptom of enterovirus 71 is a mild fever and rash illness called hand, foot and mouth disease, but in rare cases, complications can severely affect the brain.	Large epidemics of enterovirus 71 have occurred in Australia and South-East Asia since 1997. Severe neurological disease has resulted in numerous cases, including in Perth, WA.

Detailed information about our research may be found at our website at www.ichr.uwa.edu.au

Our research

Our focus on new vaccines to prevent meningitis has yielded exciting results. The first combination vaccine study (combining *Haemophilus Influenzae* type B and Meningococcal C and Y vaccines into one injection) showed no safety concerns and excellent protective antibody levels to all three vaccine components, better than if the vaccines were given separately. This has led to the next phase study for which we recently completed recruitment of 200 infants here in Perth and more than 1,100 babies Australia-wide.

The challenge of prevention of meningococcal B disease remains and we are currently trialing a new Meningococcal B vaccine. The B strain is the most common type of meningococcal disease in Western Australia, accounting for about 80 per cent of cases. Most cases occur in babies and young adults. There is currently no vaccine to protect against the B strain of this disease. This trial will examine how safe and effective the vaccine is in healthy young adults aged between 18 and 25 years of age - a high-risk group for meningococcal infection.

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 since 1992 to raise public awareness of all forms of meningitis and available 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. The Meningitis Centre actively lobbied the government for free meningococcal C and pneumococcal vaccines. More information about The Meningitis Centre may be found at www.meningitis.com.au

The pneumococcus is a significant cause of disease in Australia especially in the very young, the elderly and those with medical risk factors. The Aboriginal and Torres Strait Islander population has a higher incidence of pneumococcal disease than non-Aboriginal and Torres Strait Islanders. On January 1, 2005, after many years of lobbying by our Meningitis Centre, pneumococcal immunisation became part of the National Immunisation Schedule for all infants, adults over the age of 65 and for those who qualify as high risk.

We continue to monitor cases of invasive pneumococcal disease including collecting clinical, risk factor and microbiological data for all cases across Western Australia. This information is important so we can monitor the impact of pneumococcal vaccines.

We are also working with the Papua New Guinea Institute of Medical Research, to immunise newborns in Papua New Guinea with pneumococcal conjugate vaccine to try to reduce high death rates associated with acute respiratory infections caused by pneumococci in the first year of life. During 2005, recruitment for the study began and by the end of the year, 60 babies were enrolled.

Influenza continues to be in the public eye particularly with the threat of an avian influenza pandemic looming large, and human influenza strains continuing to cause significant disease in all ages. The effects of influenza in children are being increasingly recognised, as is their role in spreading the infection to adults. Consideration of routine influenza vaccination for children led to a study of how well the current flu vaccine works in children aged six months to eight years. The results from this study so far have found that the vaccine was safe, well-tolerated and produced a good immune response in young children. We also completed a flu study in the elderly with Fremantle Hospital to see if giving the flu vaccine into the skin (rather than into muscle) might improve responses in the elderly, who are at highest risk of disease. The study results showed that giving the flu vaccine into the skin did give better protection than when given into the muscle.

We are about to embark on exciting studies of avian influenza vaccines in children, adults and the elderly.

Our work on enterovirus 71 is providing valuable information on the origin of recent epidemic strains of the disease and may also help to identify the strains most likely to attack the brain for future analysis. We are also training scientists from developing countries in the Asia-Pacific region in molecular methods of enterovirus 71 surveillance. We have trained several scientists from Vietnam who have since commenced surveillance for enterovirus in southern Vietnam and in 2006, we will train scientists from Jakarta, Bandung and Surabaya in Indonesia so that enterovirus 71 surveillance can commence on the island of Java. We have also developed candidate vaccine strains and an experimental model to test the effectiveness of these candidate vaccines in preventing enterovirus 71 infection.

imagine....

A blueprint for happy families.

Almost every parent at some time has wished that their child came with an instruction manual. Our research has repeatedly shown the importance of parenting in shaping a child's development. So what works? Our evaluation of the community roll-out of a high quality parenting education course for parents of young children showed dramatic results for the family and for the child.

Our research continues to look at the range of risk and protective factors that affect mental health and behaviour. Importantly, we've developed strategies and information programs to reduce the burden of these problems in our community.

Social and emotional wellbeing

	About	Facts and stats
Suicide prevention research	The Ministerial Council for Suicide Prevention (MCSP) advises government and coordinates a range of State-wide activities aimed at reducing the death and disease associated with self-harm and suicide.	Australia has a rate of youth suicide which is in the top third of developed countries. In the 17-year study period 1986 to 2002 suicides accounted for 3,773 deaths in Western Australia, 3,051 males and 722 females. Males completed suicide at around four times the rate of females.
Support packs	Information and support packs designed to assist family and friends.	The Bereavement Pack can be downloaded at www.mcsp.org.au The Information and Support Pack will be available in 2006. It is the first Australian publication of its kind.
Positive Parenting evaluation	We evaluated the effects of the Group Triple P (Positive Parenting of Pre-schoolers) program on 804 families with pre-school aged children. It was the first time the program had been offered in group sessions by child and community health nurses. The families were tracked for two years after completing the program and their results compared with another 800 families in a control group.	The Group Triple P program was developed by Professor Matt Sanders at the University of Queensland and the Health Department of Western Australia, based on the Triple P Positive Parenting Treatment Program. The study results were published in the international journal *Prevention Science*.
Virtual Infant Parenting Program	Aims to reduce adverse maternal and child health outcomes associated with unplanned teenage pregnancy and parenthood.	The project is funded by Healthway and LotteryWest.

Detailed information about our research may be found at our website at www.ichr.uwa.edu.au

Our research

The MCSP maintains the WA Coroner's Database on Suicide, an on-going collection of epidemiological surveillance data on suicides by persons of all ages in Western Australia. It has provided some of the first Australian data outlining key risk and protective factors for suicide among young people and is used to monitor emerging trends, such as a recently observed increase in illicit drug use associated with suicide among young people. The Council also coordinates research into the hospital and community management of deliberate self-harm including the design and maintenance of a database within each of the three adult teaching hospitals in Perth used to monitor trends in deliberate self-harm admissions.

In 2005, the MCSP developed a unique Internet resource targeted at young people who access suicide prevention information or support through the Internet. The resource shows young people ways that they can safely access support and information on the Internet and how to respond to and support email friends who are at-risk or have indicated their intent to harm themselves. It also examines the advantages and disadvantages of using the Internet for suicide prevention information and lists websites that provide credible sources of information.

During the year, the Australian Suicide Prevention information Resource Exchange (ASPiRE) - a national information and resource system for suicide prevention that involves dissemination of new information and targets both professionals and the community - boosted its number of research articles and resources to more than 3,500. ASPiRE can be located at www.mcsp.org.au

In 2005, we developed and piloted an Information and Support Pack for those concerned about someone who is distressed or suicidal. The pack was funded by the Margaret River Friends of the Institute and piloted in their local region. It aims to address a major gap in the information resources readily available to families and friends who play such a vital role in the months and years following a suicidal crisis. This is the first Australian publication of its kind and has generated significant interest. The pack will be evaluated and updated in 2006, before being disseminated statewide and eventually nationally.

We continued to distribute the Bereavement Pack, a resource we developed based on research on the support needs of families bereaved by suicide. It provides helpful information for families during their bereavement.

Nearly 17 per cent of four-year-old children in Australia are considered to have disruptive behaviour problems. In November 2005, we published the results of the first large-scale scientific evaluation of group-based positive parenting programs, which showed that these programs reduce clinically significant behavioural problems in children by 36 per cent.

The study found that families who completed the program reported:

- Dramatically improved behaviour in children with clinically significant behaviour problems
- Significantly reduced levels of children developing later behaviour problems
- Decreased dysfunctional parenting behaviour
- Decreased parental depression and conflict and significantly lower levels of parent conflict over child rearing.

In the two years up to and including 2005, we have been recruiting female high school students to this project. All government and independent schools in each of the Metropolitan Area Health Service regions of Perth were invited to take part. 58 schools elected to participate with 1,277 students taking part and a further 1,553 enrolled as comparison subjects. The program covers health issues affecting babies and mothers including smoking, nutrition, alcohol and other drugs, physical activity and support systems. A key component of the program involves students caring for an infant simulator over a weekend period. The infant simulator realistically replicates the sleeping and feeding patterns of a six-week old infant and gives the students a brief insight into the burden a baby can have on a teen mother.

In other teen pregnancy research, we are looking at the psychological, social and biological pathways to unplanned pregnancy to develop new understandings of teenage pregnancy in Australia and more effective intervention programs. Recruitment will begin in 2006.

imagine....

The boost to children's development if they were raised in child-friendly communities with great family services and support.

The Institute is a prime mover in the national roll-out of the Australian Early Development Index -- a powerful tool for communities to see just how well their pre-school children are fairing, even before they start school. Good quality information about children's development helps communities target early intervention strategies and advocate for provision of funds where they're most needed.

There is a growing body of research which shows the importance of early brain development. How children are nurtured and stimulated in their first years of life is critical to how they perform at school and the path they take in life.

The early years

	About	Facts and stats
Australian Early Development Index (AEDI)	The AEDI project is being conducted by the Institute in partnership with the Centre for Community Child Health (CCCH) at the University of Melbourne. Funded by the Australian Government Department of Family and Community Services and Shell Australia, it involves the adaptation and validation of the Canadian Early Development Indicator (EDI) for use in Australia. 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.	Participating communities are provided with a profile of how their children are doing in comparison with the State and National benchmarks. The pilot work for the project carried out in Perth North Metropolitan Health Region has shown these community profiles to be a powerful means of mobilising community resources for improving early child development and education. The AEDI project will run for three years and it is anticipated that around 60 communities will be participating during this time.
The importance of breastfeeding	According to the Australian Breastfeeding Association, breastfeeding: • protects your baby from illness and infection • provides the correct food for your growing baby • aids the development of your baby's eyesight, speech and intelligence • promotes a special loving bond between mother and baby.	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 infant and childhood death for all children born in WA between 1980 and 2003 inclusive.

Detailed information about our research may be found at our website at www.ichr.uwa.edu.au

Our research

In 2005, Australian communities were chosen for the round two implementation of the AEDI. Twenty five communities across five States took part, with 933 teachers in 430 primary schools recording information on more than 16,756 children. The results for these communities were launched in November with major findings including:

- 23 per cent of Australian children surveyed were "developmentally vulnerable" on one or more domains of the AEDI
- 11 per cent of Australian children surveyed were "developmentally vulnerable" on two or more domains of the AEDI
- 65 per cent of Australian children surveyed were "performing well" on one or more domains of the AEDI.

Results profiles were produced for each of the participating communities and provide a demographic profile of the community and describe how children are doing on each of the AEDI domains of child development. The participating communities are now being supported to utilise their findings to map service needs and community resources for children and families and to use this for initiating community action and services to address identified needs.

The AEDI is a powerful tool for creating communities where all children can thrive and grow to fulfil their potential. It assists communities to understand how their children are doing in crucial areas of development and how they can use their results to put effort and resources into services and programs for young children so that all children make the best possible start as they enter primary school.

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. We are conducting a long-term study to investigate interactions between early and current nutrition with disease occurring from infancy through childhood.

Breastfeeding plays an essential but often underestimated role in childhood development and has long term consequences for child mental health. In preliminary analysis of the Infant Monitoring Questionnaire, we showed that children breastfed for four months or longer had higher mean scores in most of the developmental domains (communication, fine motor, adaptability and sociability) at one, two, and three years of age. Further, we showed that early breastfeeding was associated with better scores on mental health tests later in childhood. These results indicate a positive effect on development in early childhood of a longer duration of breastfeeding.

In 2005, we also conducted a comprehensive review of scientific studies on the use of baby pacifiers (dummies) and found that they interfere with successful breastfeeding. The review identified repeated studies that had found that use of dummies results in a reduction of breastfeeding duration or exclusivity. The review had also found that the use of pacifiers reduces the risk for SIDS – but the mechanism of the effect is not understood. As breastfeeding confers an important advantage on all children and the incidence of SIDS is very low, it is recommended that health professionals generally advise parents against pacifier use, while taking into account individual circumstances. The information has been published in a Best Practice Information Sheet for Health Professionals by the Joanna Briggs Institute.

Analysis of the information held in the database has resulted in the development of a "mortality profile", which describes the patterns and trends of infant and childhood death in WA over the past 23 years. Our research has a particular focus on preventable deaths including deaths attributed to Sudden Infant Death Syndrome in the Indigenous population. Whilst it is well-known that health promotion programs have been successful in reducing the risks of SIDS, what is not so widely recognised is that they have not been effective in Indigenous populations. The reasons for this are not yet clear. Our research is bringing together major researchers in SIDS with those in Indigenous child health to tackle this problem.

The first research report of the database was tabled in Parliament in May 2005 - the report and all its recommendations were accepted. The recommendations are forming the work program for the Ministerial Advisory Council on the Prevention of Deaths of Children and Young People.

imagine....

A vitamin that prevents birth defects.

Sounds unlikely, but it's true. Our researchers were part of the international team that confirmed the important role that folate plays in preventing neural tube defects such as spina bifida. Since then we've played a leading role in advocating for the fortification of food with the vitamin so that the benefits can be more widely available.

We're working hard to increase understanding about the causes of disability but also how they impact on the lives of children and their families. From greater understanding comes ways to prevent disability and to improve outcomes for children who are living with the challenges that it presents.

Understanding disability

	About	Facts and stats
Neural tube defects	Neural tube defects occur when there are problems with the development of a baby's brain, skull and spinal cord, usually during the first six weeks of the pregnancy. Most babies born with a neural tube defect will die early in life or have lifelong major disabilities such as varying degrees of paralysis of the legs and incontinence of the bowels and bladder.	Almost one in every 500 babies is born with a neural tube defect. Spina bifida and anencephaly are the most common neural tube defects. There is no cure. The vitamin folate (folic acid) can prevent up to 70 per cent of neural tube defects.
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. The *MECP2* gene on the X chromosome has been identified as a cause of Rett syndrome. There is no known cure for Rett syndrome.
Fetal alcohol syndrome	Fetal Alcohol Syndrome (FAS) is caused by maternal alcohol consumption during pregnancy and represents the most severe effects of exposure to alcohol in-utero. Children with FAS display a range of physical defects and disabilities. However the main features are cranio-facial abnormalities; prenatal and/or postnatal growth deficiency; and evidence of damage or dysfunction of the central nervous system.	FAS was first identified in the 1970's. It is a preventable condition. Data from the Western Australian Birth Defects Registry suggest a birth prevalence of 0.18 per 1,000 live births: • 0.02 per 1,000 non-Indigenous live births • 2.76 per 1,000 Indigenous live births.
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 posture, intellect, vision, hearing and speech.	Cerebral palsy is the most common physical disability in children. There is no known cure for cerebral palsy.
Down syndrome	Down syndrome is caused by an extra copy of chromosome 21 resulting in 47 chromosomes in each body cell, instead of the usual 46. The exact reason why this occurs is not known.	Down syndrome, also known as Trisomy 21, affects approximately one in every 660 babies born throughout the world. It is one of the most frequently occurring chromosomal anomalies in humans.

Detailed information about our research may be found at our website at www.ichr.uwa.edu.au

Our research

We investigated awareness and consumption of folate fortified foods by women of child bearing age in Western Australia. Before or during their recent pregnancy, 42 per cent of women had noticed labels on foods that mention folate and 33 per cent usually or always read the labels on food packaging. Overall 53 per cent of women were aware of foods that have folate added to them and the most frequently consumed folate-fortified foods were cereals (69 per cent), breads (34 per cent) and milk (15 per cent). Almost 80 per cent of women consumed foods voluntarily fortified with folate and this suggests that, should mandatory fortification be introduced, folate may reach most women providing improved opportunity for prevention of neural tube defects in Australia.

We have also looked at maternal intake of folate and other major birth defects and found that neither folic acid supplements nor dietary folate intake in women not using supplements was an important factor in the prevention of birth defects other than neural tube defects.

We continue our work on AussieRett, a five-year population-based study following Australian girls born with Rett syndrome since 1976. In 2005, we collected information from Australian families on their child's functional ability in daily living, behaviour, hand function, medical conditions and use of health and education services. We also collected genetic and clinical data and investigated which factors are most likely to be associated with early onset of seizures. We also officially set up our Consumer Reference Group and we conducted both a parent and clinician workshop.

We continue to manage an international database known as InterRett, which collects data from families and clinicians around the world. In 2005, the family questionnaire was translated into Spanish, Italian, German and French to assist non-English speaking families to participate. The online questionnaire and website was also translated into Spanish. To date the database contains over 900 cases from 28 countries satisfying the prime objective of creating a sufficiently large sample size to allow comparison of genetic and observable characteristics.

Over the past four years, we have collected data with the Australian Paediatric Surveillance Unit to determine the number of children with FAS in Australia. This shows that there were 76 reported cases that met the definition for FAS (suspected FAS or partial FAS) with 61 per cent identified as Indigenous and 76 per cent exposed to other substances in utero including nicotine (65 per cent) and marijuana (25 per cent).

We have also determined health professionals' knowledge, attitudes and practice in relation to FAS and alcohol consumption in pregnancy. Results show that of 1,143 health professionals surveyed, 12 per cent identified the four essential diagnostic features of FAS and only 2 per cent felt very prepared to deal with FAS and most wanted information for themselves and for their clients. Of the 656 health professionals who cared for pregnant women, 45 per cent routinely ask about alcohol use in pregnancy, 25 per cent provide information about the consequences of alcohol consumption in pregnancy and 13 per cent provide advice that is consistent with the NHMRC guideline on alcohol consumption in pregnancy. Health professionals have expressed an overwhelming interest to find out more about Fetal Alcohol Syndrome.

It is now known that less than ten per cent of cases of cerebral palsy in developed countries are due to problems during labour. It is more likely to be caused by a combination of factors that may include pre-term birth, multiple pregnancy, growth restriction and/or pregnancy complications and our research is looking to identify some of these combinations of factors.

We continue to maintain the Western Australian Cerebral Palsy Register 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. During 2005, new cases of cerebral palsy were added and information for the 1999 birth year is now complete. We continue to coordinate the Australian Cerebral Palsy Register, a collaboration of Cerebral Palsy Registers in all States and Territories in Australia.

Down syndrome is the most common known cause of intellectual disability, affecting 14 to 15 per cent of Western Australians receiving services because of an intellectual disability. Over the last 20 years, there has been a significant improvement in survival and life expectancy of infants born with Down syndrome, resulting in an increased demand for medical and support services.

Our Down syndrome research is looking at the health, needs and functioning of children and young adults with Down syndrome. During 2005 we completed data collection and achieved a response rate of 72 per cent. Results are expected in 2006.

Senior staff

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 the 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).

Robert Ginbey
BA BEd Grad Dip Public Sector Mgt MACE
Head of Division of Admin and Corporate Services

Mr Ginbey joined the Institute in 1995. He has taught history and economics in Western Australia and Papua New Guinea and more recently worked as a senior policy officer and senior manager of corporate services and strategic planning for both the commonwealth and state governments. He has coordinated two five yearly international reviews and the planning and opening of the Institute's current building.

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
Member of Executive, 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 Associate Professor at Curtin University of Technology. She provides expertise in infectious disease epidemiology and Indigenous health.

Bruce McHarrie
BCom CA
Member of Executive, 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.

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.

Prue Hart
BSc(Hons) MSc PhD
Head of Inflammation Laboratory

Principal Research Fellow, NHMRC and an Adjunct Associate 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).

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, housing.

Pat Holt
PhD FRCPath(UK) DSc FAA
Member of Executive, 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.

David Izon
BSc(Hons) PhD
Head of Division of Cancer Biology until December 2005

Dr Izon is interested in investigating the causes of T-cell leukaemia as a foundation for more rational and specific treatment regimens for the disease. He is examining the role of transcription factor SCL in T-cell leukaemia by utilising a GFP-based retroviral expression system to elucidate the impact of SCL overexpression on normal T-cell development and leukaemogenesis. Additionally, he is initiating genetic screens to identify novel T-cell oncogenes.

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
MD FRACP DSc
Member of Executive, Head of Division of Clinical Sciences

Professor Sly established the Division of Clinical Sciences at the Institute in 1991. He is currently Director, Clinical Research and Education, Princess Margaret Hospital for Children; Professorial Fellow and Coordinator of Postgraduate Education, School of Paediatrics and Child Health, University of Western Australia; Senior Principal Research Fellow, NHMRC; Respiratory Physician, Princess Margaret Hospital for Children.

Wayne Thomas
BSc Hons PhD
Member of Executive, 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 Walter and Eliza Institute for Medical Research. He is the chairman of the International Allergen Nomenclature Committee.

Stephen Zubrick
MSc AM PhD
Member of Executive, Head of Division of Population Sciences

Professor Zubrick is a Senior Principal Research Fellow and holds a Professorship in the Institute and 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

This Centre was established in 2001 and 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 Services, and is closely linked with the School of Paediatrics and Child Health. The Centre has collaborations with other UWA Schools and Centres including the School of Population Health and the Centre for Medical Research. The Centre agreement is to be renewed in 2006, and is included in the terms of reference for the quinquennial review of the Institute in November 2006.

Centre for Developmental Health

The Centre for Developmental Health, a joint venture between the Telethon Institute and Curtin University of Technology, has been operating since June 2001. This multidisciplinary centre brings together researchers from several disciplines in child and life-course human development with the aim of improving population outcomes in health, education and social wellbeing. This has enabled productive research collaborations between the Institute and various areas of health science at Curtin including the Centre for Behaviour Change and Cancer Control, School of Psychology, School of Nursing and the National Centre for Aboriginal Studies.

Princess Margaret Hospital for Children (PMH)

The Institute continues to have a close working relationship with PMH, which in turn is part of the statewide Women's and Children's Health Service of the Health Department of Western Australia. These important links were identified in the PMH Campus Review of Research and Education of August 2003, conducted by Professor Graeme Barnes. 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, a logical extension of recommendations from the Barnes Review. The close working relationship between medical research, clinical practice and teaching is exemplified in the important area of children's cancer and leukaemia.

Edith Cowan University (ECU)

The Institute continued a number of collaborative studies with ECU, mainly in the area of Population Sciences. In addition, in 2005, the Institute formalised its relationship with ECU through the signing of a Memorandum of Understanding addressing joint research and postgraduate teaching opportunities.

Murdoch University

The Institute was host to several Honours and postgraduate research students from Murdoch University, principally in the Division of Molecular Biotechnology. Several new collaborations are developing, not only in Biomedical and Clinical Sciences, but in Population Sciences as well.

Notre Dame University

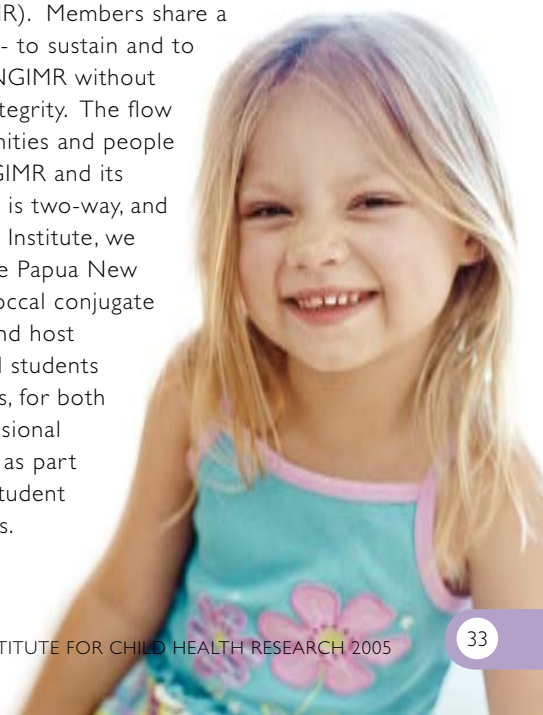
A collaboration with researchers at Notre Dame University Australia with respect to the WA Pregnancy Cohort (Raine) Study was established, with Notre Dame Senior Lecturer Dr Beth Hands awarded Honorary Research Fellow status at the Institute.

World Health Organization Collaborating Centre for Children's Environmental Health

In 2005, the World Health Organization (WHO) designated the Division of Clinical Sciences at the Institute as a Collaborating Centre. Our Institute has the capacity and expertise to make a significant contribution to research and education in the area of children's environmental health and will therefore fulfil a function in WHO's international program. Our WHO Collaborating Centre will be operational for four years from 2006.

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 jeopardizing its integrity. The flow of ideas, opportunities and people between the PNGIMR and its coalition partners is two-way, and in the case of our Institute, we are involved in the Papua New Guinea pneumococcal conjugate vaccine project, and host PNGIMR staff and students for exchange visits, for both short term professional development and as part of postgraduate student research programs.



Our commitment to the community

Consumer and Community Participation

Our activities with the UWA School of Population Health in the area of consumer and community participation are groundbreaking – we are at the cutting edge of this important aspect of research both nationally and internationally.

Our commitment to consumer and community participation made exciting progress in 2005. Some of the highlights which took place over the year include:

- the development and implementation of an Institute-wide policy on consumer and community participation
- the establishment of a joint Institute and UWA School of Population Health Consumer and Community Participation Steering Committee
- collaborating with the Health Consumers Council, Downs Syndrome Association, Arthritis WA, Diabetes Association WA, Cochrane Consumer Network, Cancer Foundation and Aboriginal Health on the Steering Committee
- The inclusion of consumer and community practices in Institute projects such as the Raine Study, Australian Rett Syndrome Study and Alcohol and Pregnancy Project
- Collaboration with the Office for Children and Youth to establish and build on opportunities for young people to be more involved in research.

2006 will see further exciting initiatives developed and new collaborations established, all of which will aim to increase and enhance consumer and community participation and add value to research at the Institute.

Privacy

The Institute is bound by the Privacy Act 1988 (Cth) and abides by the National Privacy Principles. We are committed to protecting personal information collected and held on individuals with their consent.

Improvements to our guidelines and policies were made in 2005. These include:

- the role of Privacy Officer being included in the Publications and Information Services role
- the appointment of an Assistant, Information Services to help with the maintenance of privacy information for Institute projects
- a review of the privacy procedures undertaken for all Institute projects to ensure accuracy of our records and adherence to the Institute privacy guidelines. This will continue into 2006.

All research projects undertaken by the Institute have been submitted to and approved by one or more WA ethics committees. Approvals from these committees allow researchers to obtain data directly from existing databases or approach potential study participants to seek their consent to supply us with personal information, such as name, contact details and health information.

When researchers receive completed questionnaires or other information from study participants, the name is removed and replaced by a study identity number. Computer data files and paper records are stored by this identity number. All records are secured in locked cabinets or stored on a secure computer network.

Occupational Health and Safety

Occupational Health and Safety is of great importance to us, not only for our staff and students, but for the many families and children who visit us to take part in our research projects.

Development of appropriate policy and procedures to maintain high safety standards continues to be a priority for the Institute in the area of occupational health and safety. Other priorities include conducting risk assessments to identify and evaluate workplace hazards (including those that may affect visitors), the provision of appropriate training, and the promotion of health and safety in the workplace.

In 2005, we made improvements to facilities for visitors, with a restructure of our atrium to provide more female toilets, a toilet with appropriate access for those with disabilities and a baby change room. We also continued to monitor the building to make it visitor-friendly and made recommendations to the local council on safety issues around our building, particularly footpaths, pedestrian crossings and parking.

Raising awareness in the community

The Institute's Public Relations Office

The aim of our Public Relations team is to support and promote research excellence.

In 2005, we were involved in a number of activities aimed at raising the profile of the Institute and individual research projects, and informing the public of our research.

We generated significant media interest for our research including:

- national print interest in the results of the Australian Early Development Index project
- widespread WA coverage of a new cancer gene test
- WA television coverage of both the combined meningitis and kids flu vaccine trials
- extensive print coverage of the findings from Volume Two of the WA Aboriginal Child Health Survey
- major national interest in a review of the use of dummies, including an interview on the national breakfast TV program, Sunrise.

The business breakfast mentioned earlier in the highlights section was a great opportunity for the Institute to engage and inform more than 700 Perth business people.

The circulation of our newsletter, *Under the Microscope*, continues to grow with many being sent around Australia and the world.

In 2005, we were part of the Kids Carnival during the Telethon weekend. Thousands of Perth locals discovered more about our research and were able to test their hand strength, look at their own cheek cells and extract DNA from peas.

We welcomed many people to our building for tours and seminars. Several school groups took part in interactive tours of our labs with our improved schools program including a new education pack specifically designed to enhance school excursions.

The Meningitis Centre

In 2005, The Meningitis Centre's public activities reached new heights.

The successful introduction of the pneumococcal immunisation program on January 1, 2005 was the culmination of years of lobbying by the Centre. Thousands of children were immunised, with most parents taking advantage of the free catch-up program for children born from January 1, 2003. Pneumococcal immunisation is now a permanent part of the National Immunisation Schedule for all infants, adults over the age of 65, and those who qualify as "high risk".

Other achievements in 2005 include:

- continued distribution of information to medical centres, community health centres, hospitals, child care centres and community organisations around Australia. The increased demand for information by parents also is a great sign.
- increased website activity, with more than 200 hits per day. Information on the site is updated regularly and includes disease information, immunisation information and personal stories from individuals and parents. www.meningitis.com.au
- strengthening of our volunteer peer support program with another group successfully completing the training to allow them to support others. Feedback has been very positive and we now have a fantastic group who can help others affected by meningitis.
- expanding our involvement in the international Confederation of Meningitis Organisations (COMO). Centre Chairman Mr Bruce Langoulant, was elected Vice President at the Steering Committee Meeting in Warsaw in September 2005. With Bruce in a pivotal position he is part of the team ensuring COMO gets off to the best start possible with the introduction of material and their website. www.COMOonline.org

Friends of the Institute

The Friends are a group of volunteers who make valuable and worthwhile contributions to the Institute. The Friends advocate for child health research, raise awareness of the Institute and provide financial support to various research projects.

In 2005, The Friends held a number of events including a "Back to the Swanny Stomp" night, the always successful annual ladies golf day and a Christmas brunch.

With hundreds of people attending these events, the Friends certainly help to spread the word about the work of the Institute. An Institute researcher attends each event to talk about their research that has been supported by the Friends.

These successful events allowed the Friends to support many worthy researchers and projects. The Friends also established a scholarship for outstanding research, known as the Samantha Carroll Award. This was awarded to diabetes researcher Dr Aveni Haynes.

The Friends committee based in Margaret River have continued their excellent fundraising efforts which allowed them to fund two new projects in 2005.

They supported a meningitis awareness campaign in their region and funded a pack to assist family and friends support those at risk of suicide or self-harm. The Margaret River community piloted the pack, providing important feedback as part of the evaluation.

The Margaret River Friends also became incorporated in 2005.

The Friends would like to thank and acknowledge the continued support of vice-patron Angela Bennett.

The Friends would not operate without the enthusiasm, commitment and support of the committee members. Thank you to all committee members, past and present, Perth and Margaret River, for your contribution.

Our corporate partners

The Institute is proud to acknowledge and thank our corporate partners who provide vital support to our research programs. Every partnership is a commitment that helps us prevent childhood illnesses and disabilities, strengthen communities and make a real difference to the health and wellbeing of children across Australia and the world.

The ongoing support that we receive from **Channel Seven's Telethon** and the people of Western Australia is fundamental to our success. This assistance is significant in our ability to achieve our research aims.

Shell Australia supports the Australian Early Development Index (AEDI), an innovative tool that assesses how children in a community are performing in terms of early development and readiness for school, and identify gaps in services and support for children. This project is an important plank of Shell's social investment program and provides critical assistance in implementing the AEDI throughout Australia.

The **Rio Tinto** Child Health Partnership is a unique partnership aimed at delivering improvements in the health and wellbeing of Aboriginal and Torres Strait Islander mothers and children. Rio Tinto has displayed great leadership in making this partnership a success, by working collaboratively with state and federal governments, the Alcohol Education and Rehabilitation Foundation and the Telethon Institute.

The **Alcoa** Child Health Partnership was launched in 2005 and reflects Alcoa's overall commitment to build stronger communities. The Partnership will support Professor Fiona Stanley and the Institute's population-based researchers in a major research project looking at early determinants of child health and development. Alcoa's support will strengthen the capacity of the team in both research and advocacy.

QANTAS Airways Limited provides the Institute with the capacity to travel, build collaborations and share scientific knowledge and expertise across Australia and the world. The QANTAS partnership also supports the annual New Investigator Award, an important initiative that allows a promising Institute researcher to attend an international scientific conference and visit other research organisations.

Wesfarmers Limited is committed to supporting child health research at the Institute and in acknowledgement of this support, our Atrium carries the Wesfarmers name. The support provided by Wesfarmers is vital and we are proud of our on-going association with this great Western Australian company.

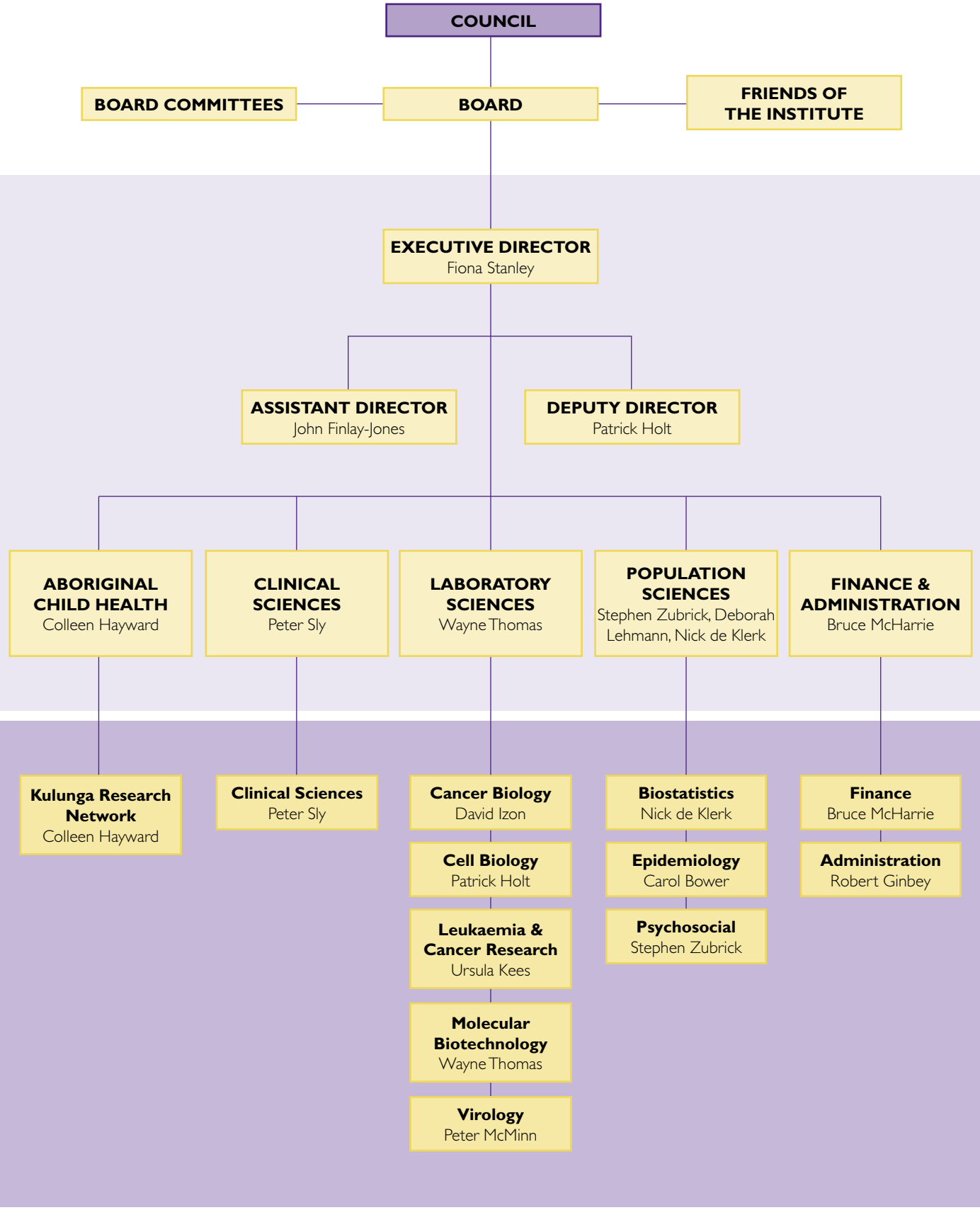
Woodside Energy Limited continued its support of the Ministerial Council for Suicide Prevention until the conclusion of the partnership in December 2005. This partnership has been integral to the development of more effective resources to aid in the prevention of suicide, particularly in young people.

KPMG continues to provide valuable advice and support to the Institute and our research programs. KPMG generously conducts the annual audit of our financial statements on a pro-bono basis, which is greatly appreciated.

Through the generous support of the **Perron Foundation**, the Institute is now able to offer the prestigious Stan & Jean Perron Fellowships. These fellowships allow the Institute to attract and retain high calibre, early-career researchers. Perron Awards will also be awarded to high achieving research students and early post-doctoral scientists to reward exceptional performance.

The Institute will continue to seek both corporate and private partnerships throughout Australia and overseas to ensure continued support for our research.

Management/Operating structure



Board of Directors

Kevin Campbell AM

Chair, Telethon Institute for Child health Research; Winner, Fiona Stanley Medal 2003.

Harvey Coates AO

MBBS MS Diplomate American Board Otolaryngology FRACS FAC FRCS(C)

Senior ear, nose and throat surgeon, Princess Margaret Hospital for Children; Clinical Associate Professor, University of Western Australia; Winner, Fiona Stanley Medal 2001.

Keith Jones

BBus CA CPA

Board member, Deloitte Corporate Finance Pty Ltd; Managing Partner, Deloitte Touche Tohmatsu Western Australia.

Jenni Ker

President, Friends of the Institute.

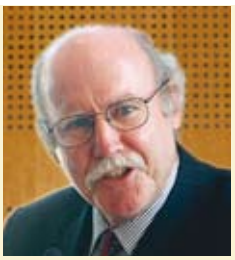
Louis Landau AO

MD FRACP

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

RDA BVSc FA CVSc PhD FTSE FAA

Principal, Foursight Associates Pty Ltd.

Fiona Stanley AC

FAA FASSA MSc MD FFPHM FAFPHM FRACP FRANZCOG Hon DSc Hon DUniv Hon MD Hon FRACGP Hon FRCPCH

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.

Committees of the Board

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.

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
Fred Stone (to August 2005)
Fiona Stanley AC

Development

Danielle Blain
Alison Bugno
Mark Ceglinski
Harvey Coates AO
Matthew Cooper
Hon Richard Court AC
Steve Davison (to April 2005)
Tammy Gibbs
Trevor Hunt
John Langoulant
Margie Livingston
Liz Mansell
Peter Mansell
Bruce McHarrie
Heather Monteiro
Lyn Nixon OAM (to January 2006)
James Smedley
Fiona Stanley AC

Finance

Keith Jones (Chair)
Kevin Campbell AM
Robert Ginbey
John Langoulant
Bruce McHarrie
Monica Spalding
Fiona Stanley AC

Intellectual Property Commercialisation

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

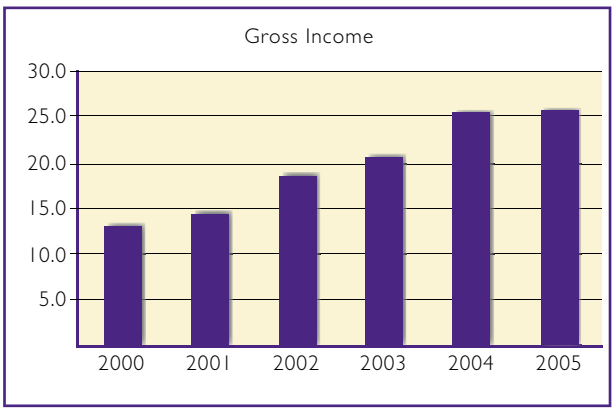
Scientific Advisory

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

Chief Financial Officer's report

The Annual Report identifies the achievements of the Institute across its various disciplines in respect of the year under review. This is measured in a variety of ways, such as research impact, discoveries, publications and, of course, financial performance.

To put each annual financial commentary into some context, I have set out below a summary of the Institute's income since 2000 to highlight the overall trend.



As the chart above indicates, the growth over a number of years has been significant. It reflects the strategy of pursuing research excellence and the consequential outcome of being successful in winning major and prestigious research grants. These grants underpin the many research activities and outcomes commented on elsewhere in this report.

A significant portion of our research income is derived from nationally and internationally competitive peer-reviewed granting bodies, such as the National Health and Medical Research Council in Australia and the National Institutes of Health in the United States. Income from commercial collaborations and Government contracts form the other main components.

Included in the above chart is the income required to support research. The research environment is complex and expensive to service if we are to provide quality support and the tools to back up our pursuit of excellence. As I have mentioned on past occasions, the State Government's Medical and Health Research Infrastructure Fund (MHRIF) has been a critical source of support, making up approximately 25 per cent of our research support income.

In 2005 we received approximately $1.4 million from the MHRIF and this was leveraged about 10 fold in terms of the level of research income it supported. This represents a significant return on the Government's investment in medical research even before the economic and social benefits of disease prevention are measured. We therefore continue to encourage the Government to not only maintain its support but also grow it.

Maintaining our competitive edge is of course essential and to this end we are pleased to have been identified by the State Government as a Centre of Excellence. As such we will be receiving approximately $1.7 million over five years to fund a major piece of research equipment relevant to our asthma, allergy and cancer activities as well as enable us to recruit bioinformaticians who are critical to the interpretation of research results.

The opportunity with the Centre of Excellence program to secure equipment and specialists is an important contributor to one of our key strategic needs. If we are to remain competitive then it is vital that we recruit scientists who are leaders in their field as well as equip them for their research. We have demonstrated that such people attract other scientists to the State, develop their skills and generate the meaningful research results for which this Institute is known. As always, funding is the key and this will be a primary component of our message to Government as to how they can effectively continue their growing support for medical research to help ensure the ongoing benefits of translating research into action.

The translation of research into action is an important aim of the Institute and commercialisation is one of a number of ways that this aim can be achieved. Our commercialisation program is growing steadily and I refer you to the separate commentary on those activities.

Given the growth in the Institute's activities as evidenced in the chart above, we have improved year on year our corporate governance procedures and this includes ensuring that we are fully compliant with the numerous regulatory authorities relevant to our work. This year we have formalised our corporate governance procedures via the adoption at Board level of a Corporate Governance Manual. A full Corporate Governance Statement is included in our 2005 Statutory Accounts.

As I mentioned above, underpinning research excellence is excellent research support, and I would again like to thank the administrative and research support personnel for their important contribution.

Bruce McHarrie
Chief Financial Officer

Commercialisation and biotechnology

Translating our research into action is one of our primary aims and industry plays a vital role in creating that link between our scientific discoveries and improved health outcomes for the public. Related benefits flow – for the Institute there is the added income to pursue further research, but in addition, there is the contribution to the growth of the biotechnology industry in Australia.

Industry involvement can be in many forms, including research collaborations, licence arrangements and spin-off companies. Our research collaborations are with major and well-recognised pharmaceutical and biotechnology companies, including GlaxoSmithKline, Merck Sharp & Domhe, Pfizer, Wyeth and Amgen. These collaborations typically help us progress basic laboratory research in areas of common interest.

A particular highlight of 2005 was the public listing of our first spin-off company, Phylogica Ltd. Phylogica was founded and incorporated in 2001, although the technology it has since developed was in formation for a number of years prior. Having incubated the early development of the company at the Institute, external investment has enabled the company to establish independence and move rapidly ahead with its technology development. The company is focused on the development of drug candidates for the treatment of inflammatory conditions and has made notable advances in areas such as rheumatoid arthritis, stroke and burns. The underlying technology aims at blocking the interaction of proteins at the cellular level that are involved in inflammatory conditions. The blocking of such interactions can be achieved without disrupting the healthy interaction of other proteins.

Our second spin-off company, Advanced Diagnostic Systems Pty Ltd (ADS), was formed in 2003. The aim of ADS is to develop an asthma and allergy prognostic and diagnostic system. To help in this endeavour, we have attracted investment funds from the United Kingdom and have collaborated with a major international diagnostics company.

Other opportunities in development include a method to detect the presence or absence of certain tumour suppressor genes. The key advantage of this technology is the potential for being able to tailor treatment to suit the cause of related cancers with the aim of minimising the likelihood of relapse. In addition, we are patenting discoveries in the field of gene expression in relation to leukaemia. Again, we expect that our research findings will be significant in being able to tailor the treatment to best match the cause of the disease.

Various other opportunities are under review and these will be reported on as they develop further.

Phylogica is developing an innovative drug treatment that could limit the damage caused by burns and encourage skin tissue regeneration.

The company has joined forces with the McComb Foundation, headed by Clinical Professor Fiona Wood, to progress the use of Phylogica's Phylomer® drugs in the treatment of burn injuries.

Phylomers® are a unique set of small protein fragments identified and owned by Phylogica that block the protein-protein interactions in cells that lead to disease.

Pictured above are the Telethon Institute's Professor Fiona Stanley, Phylogica's Dr Paul Watt and The McComb Foundation's Clinical Professor Fiona Wood.

Administration and Corporate Services

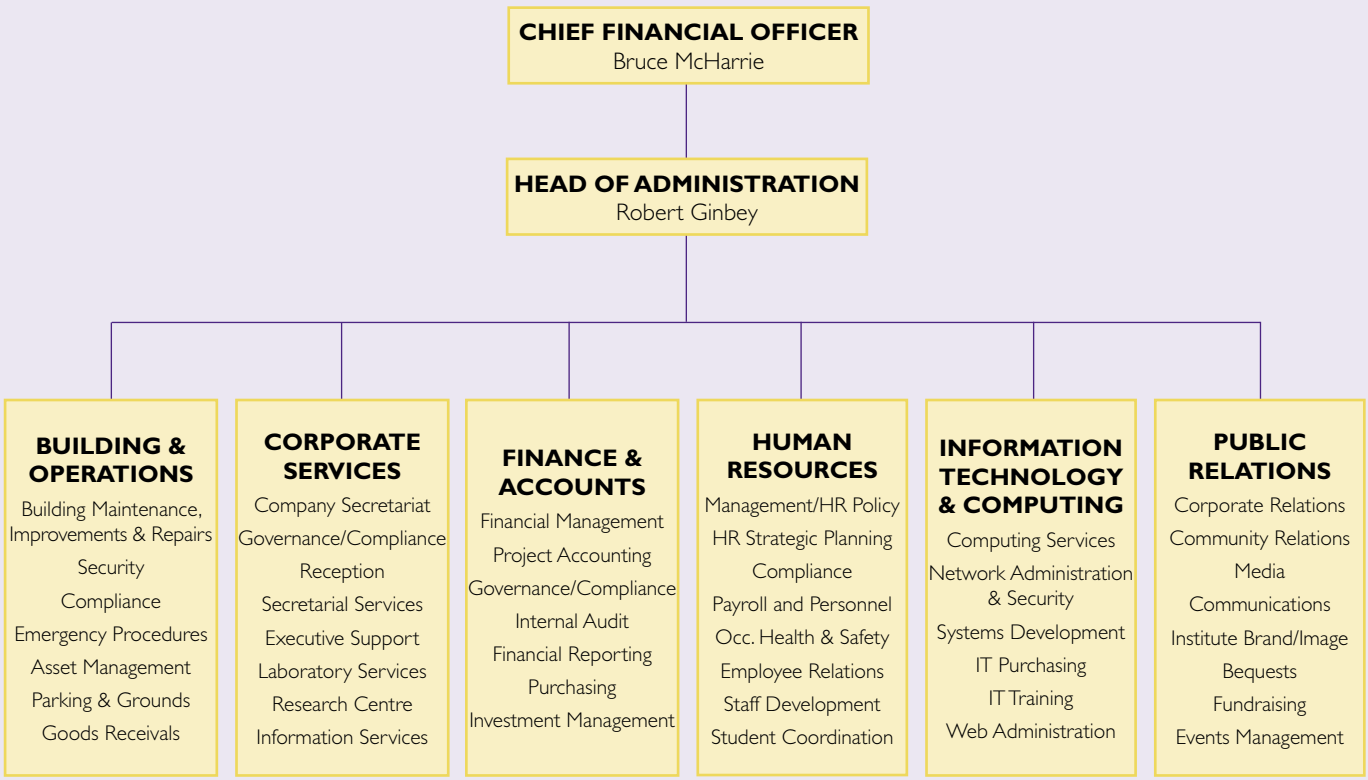
The Administration and Corporate Services Division always strives to provide the very best support services to our research teams. We constantly look for new and innovative ways to improve the services we offer.

Highlights for 2005 include:

- implementation of a new policy that requires all staff to obtain a police check.
- the creation and appointment of a new position of Compliance Officer, with responsibility for several areas of legislative compliance such as Radiation Safety, the Australian Quarantine and Inspection Service, and research ethics and welfare.
- continuing to provide a flexible and family-friendly workplace.
- improving staff communication with a weekly email newsletter.
- extensive salary packaging to help attract and retain the best researchers and to benefit employees.
- an upgrade of our post-graduate student facilities to include dedicated long-term and short-term computer stations and secure lockers.
- upgrading of our intranet to include IT and Operations service desks to improve the tracking and monitoring of jobs and support requests.
- offering media training to our researchers to better equip them for talking to the media about their research projects.
- effectively managing the continued increase in staff and students and their respective accommodation requirements.
- the training and appointment of Equity Contact Officers to ensure a work environment free from discrimination and harassment where all staff and students are treated in a fair and just manner.
- preparing for the quinquennial review of our Institute which will take place in November 2006.
- an improvement in reporting to the Board of Directors, particularly in the area of finance and accounting.
- the undertaking of a risk management planning process consistent with Standards Australia guidelines and as part of our own strategic planning.

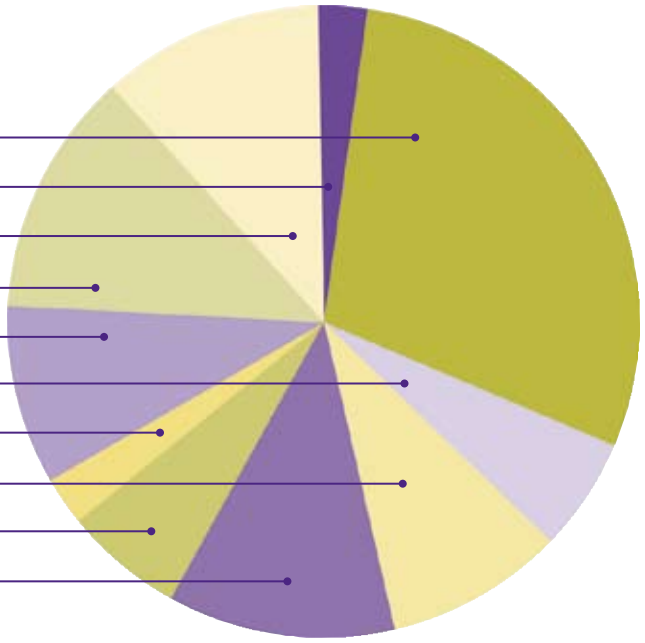
We look forward to continuing to support research excellence at the Institute.

Robert Ginbey
Head of Division of Administration and Corporate Services

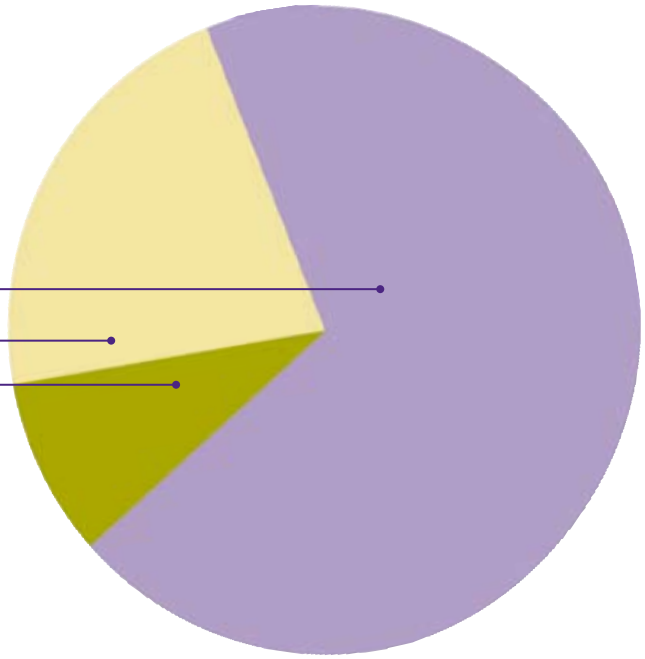


2005 - The year in brief

INCOME	Amount	%
Australian competitive grants	7,445,896	29.1
Other competitive grants	591,624	2.3
Government contracts	2,954,806	11.6
Commercial income	3,229,389	12.6
Overseas grants	2,319,886	9.1
Other grants	1,512,618	5.9
Miscellaneous income	648,570	2.5
Donations, fundraising, bequests & sponsorship	2,277,684	8.9
Investment income	1,555,169	6.1
Research support	3,036,075	11.9
Department of Health WA 1,469,070		
University affiliations 733,754		
Other 833,251		
Gross income	**25,571,717**	**100**
Deferred income	(4,405,140)	
Net Income	**21,166,577**	



EXPENSES		
Scientific research	15,406,680	69.3
Research administrative and building services	4,772,161	21.5
Depreciation and provisions	2,038,995	9.2
Total	**22,217,836**	**100**
NET LOSS	**(1,051,259)**	



STAFF AND STUDENTS	2005	2004	% change
Total number of staff as at December 31 (paid and seconded)	325	320	1.6%
Total number of honorary and visiting scientists during the year	63	57	10.5%
Total number of postgraduate students during the year	52	56	-7.1%
TOTAL	**440**	**433**	**1.6%**

Research income

Australian Competitive Grants	
Australian Research Council	668,271
Cystic Fibrosis Australia	15,724
National Health and Medical Research Council	6,724,774
National Heart Foundation Australia	37,127
	7,445,896
Other Competitive Grants	
Allergy Research Foundation	62,500
Asthma Foundation of Western Australia	1,000
The Cancer Council of Western Australia	41,000
Community Health and Tuberculosis Australia	48,562
Healthway	257,709
RAINE Medical Research Foundation	180,853
	591,624
Government Contracts	
Department for Community Development, Western Australia	93,000
Department of Education and Training, Western Australia	38,000
Department of Family and Community Services	100,000
Department of Health and Ageing	54,826
Department of Health, Western Australia	1,694,614
Department of Housing and Works, Western Australia	56,150
Department of Justice, Western Australia	48,000
Department of The Premier and Cabinet, Western Australia	144,545
Disability Services Commission, Western Australia	42,000
Food Standards Australia New Zealand	40,909
Office for Aboriginal and Torres Strait Islander Health	445,855
Office for Children and Youth, Western Australia	61,907
Office of Aboriginal Health, Family and Social Policy	135,000
	2,954,806
Commercial Income	
Advanced Diagnostic Systems Pty Ltd	1,276,870
ALK-Abelσ A/S	310,955
Amgen Inc	18,866
Avantogen Limited	111,250
Aventis-Pasteur SA	203,013
CSL Limited	104,500
GlaxoSmithKline Australia Pty Ltd	540,023
MedImmune Inc	18,927
MNL Pharma Limited	80,895
Pharmacia Diagnostics	87,000
Phylogica Limited	110,692
PPD Development	15,950
Rio Tinto Services Ltd	135,000
UCB S.A. Pharma	15,500
Woodside Energy Ltd	85,000
Wyeth Ayerst	100,372
Miscellaneous	14,576
	3,229,389
Overseas Grants	
Cystic Fibrosis Foundation Therapeutics Inc	156,704
International Rett Syndrome Association	56,345
National Institutes of Health	1,584,120
Wellcome Trust, UK	505,230
World Health Organization	17,487
	2,319,886
Other Grants	
Alcohol Education & Rehabilitation Foundation Ltd	135,000
Children's Leukaemia & Cancer Research Foundation	266,203
Curtin University of Technology	36,437
Friends of the Institute for Child Health Research	29,696
Mission Australia	10,000
Murdoch University	37,777
Princess Margaret Hospital for Children	90,021
The Royal Australian College of Physicians	23,000
The Smith Family	18,182
The University of Western Australia	866,302
	1,512,618
Miscellaneous income	648,570
TOTAL	**18,702,789**

Our supporters

"We firmly believe that every child has the right to live a life free of pain, disease and disability with the strength to enjoy all that life has to offer. This is the reality of our mission." - Professor Fiona Stanley AC

Our supporters can **imagine** a world free of childhood disease and disability, where every child is given 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 bring our **imaginative vision to reality**.

Your support is, as always, greatly appreciated.

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

telephone - 9489 7777

email - PR@ichr.uwa.edu.au

website - www.ichr.uwa.edu.au

Dr Louisa Alessandri Memorial Fund

The Dr Louisa Alessandri Memorial Fund (LAMF) perpetuates the work of a notable and much loved past Institute epidemiologist through a volunteer charitable organisation established:

- to promote education, research and opportunities for people with disabilities,
- to provide a scholarship to assist students with disabilities to realise their career aspirations,
- to support public lectures that exemplify Louisa's values, and
- to bestow an award of excellence and commitment to research.

In 2005 the Scholarship was awarded to Amy Kaye who is enrolled in a Bachelor of Economics degree at UWA, with Kevin Medhurst, Ann O'Neill and Hayden Wilson being presented with Achievement Awards.

The annual Oration was delivered by Fiona Shepherd, 2005 WA Young Australian of the Year, with the annual LAMF Award for Excellence and Commitment in Research presented to Institute employee Leanne Scott.

Mike Schon-Hegrad Memorial Fund

The Mike Schon-Hegrad Memorial Fund was established in 2005 for the purpose of promoting excellent research in child health.

Mike Schon-Hegrad, an integral member of the Institute team, sadly passed away in 2002. His legacy has inspired an annual lecture series at the Institute, encouraging prominent researchers to promote the latest in child health research to a Western Australian audience.

In 2005, the inaugural lecture was presented by Institute Deputy Director and Head of the Division of Cell Biology, Professor Patrick Holt.

The fund also supports The Mike Schon-Hegrad Incentive Award, awarded to an Institute staff member who demonstrates the innovative use of Information Technology or Management. The Award can contribute towards the cost of professional expenses related to Information Technology or Management or for professional development purposes.

The 2005 Award was presented to Alison Anderson, a researcher with the Institute's international Rett syndrome study.

imagine …

How it would feel to ***make a real difference*** *to the lives of children, not just here, but around the world.*

At the Telethon Institute for Child Health Research, we're doing more than imagining. We're working hard to turn our vision into a reality because EVERY CHILD deserves the best start to life.

TELETHON INSTITUTE FOR CHILD HEALTH RESEARCH

Proudly supported by the people of Western Australia through Channel 7

Affiliated with the University of Western Australia, Curtin University of Technology and Princess Margaret Hospital for Children

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