



Annual Report 2004



PREVENTION
INNOVATION
DEDICATION

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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.



Prevention.... is our aim. While more effective treatments are important, how much better it would be if we could stop diseases, disorders and disabilities in their tracks, before they emerge to damage the life of a child. Sounds like a dream? Not to us. These problems are caused by a complex interaction between genetics and environmental factors. If we can map the routes that lead to disease, we can identify early opportunities to stop it.

Innovation... is what happens when you bring together a critical mass of outstanding minds. The Institute's collaborative, cross-disciplinary approach is at the cutting edge of medical research.

Dedication... is what you get from the more than 400 people employed at the Telethon Institute who have committed themselves to improving the health and life chances of children, not just in Australia, but throughout the world. We know that it's important work and we're proud to be doing it.

Chairman's message



We were proud to celebrate 2004 as the fifteenth year of research operations for our Institute. Following some challenging early years, the Telethon Institute for Child Health Research is now recognised nationally, and internationally, as a leader in child health and medical research.

The benefit-cost analysis undertaken for the Institute by the highly reputed Centre for International Economics, and commissioned by the Western Australian Office of Science and Innovation, provided more than ample evidence of the importance of our asthma and folate research programs and of the work of the Institute overall. Compelling evidence of this kind must be wonderfully reassuring to the governments, business corporations and many members of the public of the economic and social value in financially supporting this Institute.

For the first time in 2004, the Institute exceeded the \$16 million mark for research income. National and international peer reviewed competitive grants made up more than 50% of the total, with State and Federal Government contracts and commercial research contracts making up an important balance. Our numbers now exceed 400 staff and students and the Board is very conscious that further growth must be carefully planned and managed.

Underpinning the success of the staff in their research endeavours, has been the stability and security provided by the Capital Investment Fund. This initiative of the Board just over ten years ago has now exceeded \$15 million. This reflects the wisdom of its founders, the overwhelming generosity of our donors, and careful management. We are grateful to all contributors to the fund and to successive fund managers, most recently JANA, for helping towards our current target of \$30 million. Such a quantum will provide the Institute with the solid financial foundation to build on the research successes of the staff and students who dedicate their lives to child health research.

Another hallmark has been the development of Phylogica, the first commercial venture of the Institute to be publicly listed on the Australian Stock Exchange. The Board is extremely proud of all of those who have contributed to the development of Phylogica. This is one of a number of commercial ventures now underway at the Institute. They reflect both the quality and versatility of Institute staff and are an indication of the foresight of the Board and senior staff who decided to embark on such a journey several years ago.

The Board is aware of some major challenges for the Institute at this stage of growth and maturity. A comprehensive risk management strategy is high on the list. As we prepare for the next five yearly review of the Institute in 2006, we are increasingly aware of the need to strategically plan and manage the next five years and beyond.

A key to our success will be a review of and renewed commitment to the purpose and the aims of the Institute and a clear articulation of the research programs to be undertaken. Growth of any kind must be sustained and guided by the knowledge of the equipment and other infrastructure resources that underpin a successful research institute.

To succeed we must nurture our strategic partnerships and alliances, at state, federal and international levels. Our partners and allies themselves of course are carefully planning the way ahead. By working together we can achieve our mutual goals.

We are grateful for the support that we have received in many different ways from the Federal Government and from the State Government. We acknowledge the mutually rewarding centre agreements with the University of Western Australia, and with Curtin University and we have strong collaborations with other universities and research institutes.

As a member of the prestigious Australian Association of Medical Research Institutes we are a member of a very strong family around the nation, and more recently we are closely linked with the Papua New Guinea Institute of Medical Research, and with medical research groups in Taiwan, East Malaysia, Vietnam, Canada and New Zealand, among others. We also have developing links with the World Health Organization. The Institute is a member of the Australian Research Alliance for Children and Youth.

We remain indebted to our major donors who have formed a strong partnership with the Institute including Telethon, Wesfarmers, Rio Tinto, QANTAS, Woodside, Shell, Alcoa, Stan and Jean Perron, and to the many businesses, schools, families and individuals who financially support the work of the Institute.

I would like to acknowledge the work of the Friends of the Institute, based in Perth and in Margaret River, for the outstanding support that they continue to provide to staff and students and to individual research projects.

It is with sadness that we learned of the passing away of two people who each made a very significant contribution to child health and medical research in Western Australia. I would like to acknowledge their contribution to our Institute and to the children of Western Australia.

Mr G. R. (Roy) McCarter was the first Chairman of the Board of the Princess Margaret Children's Medical Research Foundation (PMCMRF) and served in that role from 1969 to 1985. It was with great pleasure that in 2003 our Director was able to celebrate Roy's one hundredth birthday with former Board colleagues and PMCMRF researchers in the Board Room of the new building. Roy McCarter passed away in December 2004 at the age of 101 years.

Dr Patricia Ryan was a member of the Scientific Advisory Committee of the PMCMRF from 1985 until 1990, and a Board member of the Institute from 1990 to 1994. Pat continued on as a Council Member of the Institute until her death in 2004.

May I once again congratulate Professor Fiona Stanley and her outstanding team at the Institute, and to encourage them to build on their success over the past fifteen years.

Finally I would like to acknowledge the contribution to the Institute by Board Members, Mr Michael Daube and Ms Rebecca Maslen-Stannage, both of whom retired from the Board during 2004, and to Mrs Marilyn Stewart, who ended a four year term as President of the Friends and ex officio member of the Board early in 2005. I would like to welcome to the Board in 2005, Mr John Langoulant and Mrs Jennifer Ker, the incoming President of the Friends.

May I thank all members of the Board for their commitment to the Institute and for the rigour and diligence that they apply as members of the Board. I would also like to thank all of those who are members of the Council and of the various committees of the Board for the invaluable contribution that they make to the Institute.

Kevin Campbell AM

Chairman of the Board.



Director's report



Team of Champions ...

Someone once said that "a champion team will always beat a team of champions." This is beautifully illustrated by the Institute's activities in 2004.

The Institute has been very successful in recent years, and particularly so in 2004, in securing a range of multi-million dollar research grants, each addressing topics or themes that require a research capacity only achievable through the establishment of sizeable teams and collaborations. As well, we have developed strong teams for many other national activities.

Recent examples where the Institute has taken a national leadership role include:

- The National Health & Medical Research Council (NHMRC) Program Grant "Determinants of child health and development: populations, partnerships, pathways and prevention"
- The Australian Research Council (ARC) Linkage Project Grant "Developmental pathways to health, education and delinquency outcomes in Western Australian children: a holistic approach to inform early intervention strategies"
- The NHMRC Capacity Building Grant in Population Health Research "Not just scholars but leaders: learning circles in indigenous health research"
- The WA Aboriginal Child Health Survey
- The Rio Tinto Child Health Partnership

The majority of the national competitive grants have been won in partnership with researchers at several WA universities, in particular The University of Western Australia and Curtin University.

One also features significant collaboration with WA Government Departments - for example the ARC Linkage Grant noted above, with the Departments of Health, Education and Training, Community Development, and Justice, the Disability Services Commission and the Office for Children and Youth. Another has the Institute working with a major industry partner and the governments of several States/Territories - The Rio Tinto Child Health Partnership, with the Western Australia, Northern Territory and Queensland governments, and the Alcohol Education and Rehabilitation Foundation, established by the Commonwealth. Also the WA Aboriginal Child Health Survey has been a major state and national collaborative activity, not only with government, but with the Aboriginal community and the non-government sector.

The establishment by the flagship national granting bodies, the NHMRC and the ARC, of programs supporting research collaboration and intellectual infrastructure has provided the Institute a further opportunity to work with others nationally either in a support role (NHMRC Enabling Grant: A national population-based genetic epidemiology, biospecimen and bioinformatic resource) or as a lead agency (ARC Network Grant: "ARACY/ARC Research Network: Future Generation").

The Institute has been able to meet the demands of both national and international granting bodies that are favouring large-scale, collaborative and multidisciplinary research. This is a testament not only to the quality of the team of researchers brought together in each instance, but also to the wisdom of the approach we have typically taken to structure the applications and to present the teams and their abilities and achievements.

This has involved for each grant, very detailed planning over a long period of time by an extended team of researchers, chief or lead investigators, and associate or partner researchers. The sequence is complex, with detailing the science being a major but not sole part. Partnerships and linkages have to be forged, often underpinned by Memorandums of Understanding and contracts, and necessary infrastructure has to be acquired. A key and appreciated aspect of our success has been the involvement of staff who are often not the lead investigators who facilitate the grant-writing process, providing the continuity and help maintain momentum in a demanding process.

In order to maintain its exceptional record of success in acquiring these major, multidisciplinary grants the Institute gives major emphasis to ensuring that it can provide a high quality infrastructure for research - not just the physical infrastructure and contemporary technology base, but the intellectual infrastructure that sustains the research planning and grant-writing process. The unsung heroes and heroines of these champion teams are those providing support - be it in obtaining up-to-date references, negotiating with our partners, managing the accounts or providing computer expertise - in all aspects we're provided with exemplary service from our Administration team.

What is now clear is that the opportunities identified in the establishment of this Institute are now coming to fruition. One of these was the bringing together of different scientific disciplines to “unpack” modern childhood epidemics – such as asthma, psychological problems and suicide and more recently, obesity. The asthma team of basic, clinical and population scientists has made a huge contribution to knowledge globally, progressing now, via international collaborations, to test primary prevention strategies in several countries. The multi-centre study of the effects of genes and environment in common acute lymphoblastic leukaemia is another example of excellence in collaboration being run from this Institute.

Underpinning these important collaborations are the Institute’s unique data resources. Our population data and cohort studies are now a major reason for our grant success in an increasingly competitive process. In WA we have data on ALL births matched to ALL disease outcomes and other child and youth problems. Such data occur in very few other centres anywhere. It enables us to provide complete and unbiased descriptions and analyses of most problems, and to see how they track over time in response to changes in the environment (physical, social, chemical) or to interventions aimed at reducing them. We are now reaping the direct benefits of investing in these databases and cohorts in the early years of our history. They become even more important as we unravel all the implications of the human genome.

We have, again in collaboration, participated in best practice processes to ensure that such data are used for public good and conform to the highest standards of privacy protection. People in the community should demand the best information about their health, how to improve it, and whether their health services are effective and safe. They also need to be reassured that the detailed information collected on them is only used for important health issues and is never used to identify them individually.

Flowing from that is the recognition of the important role of consumer participation in research. The Institute supports the National Health and Medical Research Council and the Consumers’ Health Forum Statement on Consumer and Community Participation and is actively working on a detailed project to expand and build on current consumer and community participation. This is so important – not only do we have a responsibility to report back to the community, but also to be responsive to the community’s priorities for research.

Thus, the Institute is committed to excellence across all of its activities – the science to win grants, the collaborations to ensure broad coverage, understanding and respecting consumer participation, and best practice in the use and handling of all data that we are privileged to access.

2004 has been another great year for this Institute. As Director, I am pleased and proud of our success. I thank all of the staff and students, the Board and hard working committees and our wonderful Friends of the Institute. They all put in a large effort because they believe in what we do.

To our donors and supporters, thank you too. Collectively we will continue to work hard to achieve our goals of improving child health and wellbeing.

Fiona Stanley

Director



RESEARCH

Divisional highlights

	Who we are	What we do
Cancer Biology	A team of biomedical researchers, headed by Dr David Izon.	We focus primarily on a gene (SCL) which is essential for normal blood cell maturation. We identify novel genes which cause T-cell leukaemia using cDNA library screening. We are also interested in the role that the gene SCL plays in brain development.
Cell Biology	A team of researchers focused on asthma and atopy, innate immunity and paediatric vaccines. The Division is headed by NHMRC Senior Principal Research Fellow, Professor Patrick Holt.	Focus primarily on the mechanisms underlying susceptibility to inflammatory diseases in the respiratory tract, in particular those caused by allergy and/or infections.
Children's Leukaemia and Cancer Research	Headed by Professor Ursula Kees, this research Division is a member of the US-based Children's Oncology Group, the largest childhood cancer study group.	Research on childhood leukaemia and brain tumours with a focus on three areas: the identification of genetic alterations which underlie childhood cancers, the role of the HOX11 gene in T-cell acute lymphoblastic leukaemia, and the development of a new cancer drug discovery platform.
Clinical Sciences	We combine basic and clinical sciences in a team headed by Professor Peter Sly, NHMRC Senior Principal Research Fellow.	The division focuses on research in the areas of respiratory physiology, clinical asthma studies, cystic fibrosis and vaccine trials. The division also has a growing prominence in environmental health.
Kulunga Research Network	Managed by Colleen Hayward, the Kulunga Research Network is a joint initiative between the Telethon Institute and the WA Aboriginal community (through WA Aboriginal Community Controlled Health Organisations).	The aim of Kulunga is to build capacity in Aboriginal research. A team of Aboriginal researchers and staff oversee the Aboriginal child and maternal health research programs of the Institute.
Molecular Biotechnology	Headed by NHMRC Senior Principal Research Fellow, Professor Wayne Thomas and NHMRC Principal Research Fellow Associate Professor Prue Hart, researchers in this Division have a particular focus on understanding and treatment of inflammation and allergy.	Our research concentrates on: <ul style="list-style-type: none"> indoor allergens provoking allergy and asthma such as the domestic cat and house dust mite how the body regulates inflammatory responses in arthritis how sunlight affects our immune system and its relation to skin cancer and asthma.
Population Sciences	A team of around 150 staff and students, headed by Professor Stephen Zubrick, working in epidemiology, biostatistics, genetic epidemiology and psychosocial sciences, and collaboratively with government, corporate and non-government sectors.	The division strives to document the burden of disease in children and young people and assess causal pathways that lead to disease or maintenance of health, and assess the significance of these findings for the prevention of disease and the promotion of health.
Virology	Headed by Dr Peter McMinn, this team of researchers works collaboratively on a range of inter-related viral studies.	This division aims to understand how viruses cause disease within the central nervous system. The research covers a range of activities including molecular studies of viral encephalitis, the development of community surveillance for viruses causing central nervous system infections and the development of improved diagnostic methods.



Key highlights

We are leading the world in our research into SCL in the brain and the crucial role this gene may play in brain development.

We have exploited SCL's role as an ideal genetic marker for the program of blood cell development in the embryo, to show for the first time a direct lineage relationship between blood stem cells in the embryo and the adult.

With the Divisions of Clinical Sciences and Molecular Biotechnology, we consolidated the third year of our five year National Health and Medical Research Council Asthma Program Grant.

We are organising a new international clinical trial on asthma/allergy prevention in high risk children, due to commence in 2006.

Published the first study to characterise the way that white blood cells from the newborn recognise and respond to common allergens in the environment.

Professors Patrick Holt and Peter Sly developed a radical new model for asthma prevention which was published in the Nature Immunology journal, and has attracted strong international interest.

We are developing a novel genetic system called 'the discriminator blocker trap' to identify potentially superior cancer drugs.

We have identified several genes of interest that function in the regulation of brain tumour cells.

Our research featured in a documentary for ABC TV's Catalyst program. The documentary called 'Stories from a children's hospital: Chloe's Story' was aired in October 2004 and was nominated for a 2005 Logie Award for most outstanding documentary.

We developed techniques to successfully culture epithelial cells from children with lung diseases.

We developed new models of sustained allergic sensitisation.

New techniques for measuring absolute lung volume were established.

We have been working on understanding the mechanisms involved in T-cell activation.

We successfully obtained funding from the US Cystic Fibrosis Foundation to determine early detection of lung disease in infants and young children with cystic fibrosis.

We are working to establish a WHO Collaborating Research Centre for Children's Environmental Health.

Volume One of the WA Aboriginal Child Health Survey was launched in June.

We won a prestigious Indigenous Capacity Building Grant from the National Health and Medical Research Council that will support ten new Indigenous researchers over five years.

We have unravelled some of the differences between allergic and non-allergic children in their responses to components of house dust mite that induce allergy.

We have identified changes in cells that can regulate immune responses following exposure to ultraviolet light. This helps to explain how sunlight can alter the immune system.

We launched a major national study of the causes of acute lymphoblastic leukaemia.

We won a prestigious Linkage Grant from the Australian Research Council.

The Australian Early Development Index project was launched and the first sites announced.

The genetic trigger for Rett Syndrome was identified.

The first report of the Intellectual Disability Exploring Answers (IDEA) database was released.

Follow-up of the growth and overall development of Raine Study children has revealed absolutely no harmful effects of the repeated ultrasound scans in pregnancy, despite an initial concern that the repeated scans experienced by approximately half the women enrolled in the Study may have caused a very slight decrease in fetal growth for some children.

We are establishing an international collaborative study of the molecular epidemiology of enterovirus 71 in the Asia-Pacific region and training scientists from this region, in particular Vietnam, Indonesia and Malaysia, in molecular methods of enterovirus 71 surveillance.

We have determined the complete DNA sequence of two local enterovirus 71 strains and full-length infectious cDNA clones have been constructed.

RESEARCH

Aboriginal child health

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

	About	Facts and stats
WA Aboriginal Child Health Survey	A survey of Indigenous children aged zero to 17 years that details the factors that contribute to significantly higher death rates, illness and disability in comparison with other Australians, as well as identifying resilience factors.	<p>It is the most comprehensive survey of Aboriginal children ever undertaken.</p> <p>It took five years of planning, two years in the field.</p> <p>Information was collected on more than 5,200 Aboriginal children in WA.</p> <p>Interviews were conducted with 11,300 family members, 2,000 families, and more than 3,000 teachers.</p> <p>We worked in close collaboration with Aboriginal communities and agencies.</p>
Otitis Media	<p>Otitis media (middle ear infection) can seriously affect childhood development, school performance and subsequent social and economic wellbeing.</p> <p>Aboriginal and non-Aboriginal newborn babies were followed until two years of age to investigate causal pathways to otitis media and look at demographic, socio-economic, environmental, microbiological and immunological factors putting children at high risk.</p>	<p>Peak prevalence for otitis media of 72 percent in Aboriginal children aged 5-9 months.</p> <p>Peak prevalence for otitis media of 40 percent in non-Aboriginal children aged 10-14 months.</p> <p>29 percent of Aboriginal and 5 percent of non-Aboriginal children had a perforated eardrum.</p> <p>Hearing loss was detected in 65 percent of Aboriginal and 23 percent of non-Aboriginal children at 12-17 months.</p>
Rio Tinto Child Health Partnership	<p>Developed to deliver improvements in Aboriginal and Torres Strait Islander child and maternal health. Aims to achieve this through the delivery of three projects:</p> <ul style="list-style-type: none"> • modelling the WA Aboriginal Child Health Survey for the NT and QLD • reducing prenatal exposure to alcohol and tobacco • enhancing workforce capacity. 	<p>Partners include:</p> <ul style="list-style-type: none"> • Rio Tinto • the Alcohol Education and Rehabilitation Foundation Limited • WA government • NT government • QLD government and • Telethon Institute for Child Health Research.
Swimming pools project	This study is assessing the effects of swimming pools on the ear and skin health of Aboriginal children in two remote communities - Jigalong and Burringurrah.	<p>The study began in May 1999.</p> <p>Communities have been visited every six months, during summer and winter.</p> <p>Communities adopted a "no school, no pool" policy.</p> <p>Disease has declined over a five-year period.</p>



Researcher Profile

Dr Cheryl Kickett-Tucker

Post Doc Research Fellow, NHMRC Indigenous Capacity Building Grant

Cheryl Kickett-Tucker is proud to be Noongar. And she wants to ensure that her two children, Jaylon and Sarah, grow up proud too - knowing where they come from and who their people are.

Cheryl is passionate about using her research to make a real difference to the lives of Aboriginal children and their families. "As a mother and aunty to 21 nieces and nephews, I am affected on a daily basis by the issues and concerns faced by Aboriginal kids and this is a driving factor in my research," Cheryl says.

Determined to conduct her work with the utmost integrity, Cheryl also wants to ensure that she always upholds the values and ethics of her people. "I have an ability and a driven passion to help my people. I want to ensure that the knowledge I access from others is a true reflection of the people...so it can be utilised in such a way that makes a 'real' and 'sustainable' difference for Aboriginal people."



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

Our research

In June 2004, the first volume of findings 'The Health of Aboriginal Children and Young People' was launched to significant national and international acclaim.

Key findings show that:

- about 48 percent of Aboriginal people aged 15 to 19 attend no formal education (vs 24 percent of non-Aboriginal people)
- traditional Aboriginal language loss is occurring at 20 percent per generation
- low intergenerational transfer of financial, human and social capital
- no apparent social gradients in health outcomes – not even the relatively “well off” Indigenous families have better child health outcomes

The findings highlight the need to:

- reduce rates of early teenage pregnancy
- reduce rates of childhood infectious disease
- improve nutritional knowledge and access to affordable nutritious food.
- improve rates of contact of Aboriginal families and children with primary health care services.
- reduce rates of tobacco and alcohol use – particularly in pregnant women.

Field work for this study was completed in 2004. 436 saliva samples were collected (for immunological investigation) and 509 nasopharyngeal specimens (to detect bacteria and viruses in the upper respiratory tract) from Aboriginal babies and 878 saliva samples and 1050 nasopharyngeal specimens from non-Aboriginal children.

Findings include:

- crowding (number of people per room) in Aboriginal households and the presence of other children in non-Aboriginal households predicted early pneumococcal carriage, a risk factor of otitis media
- Aboriginal children exposed to environmental tobacco smoke are three times more likely to develop otitis media than unexposed children.
- Aboriginal and non-Aboriginal children living with other children are at increased risk of developing otitis media
- non-Aboriginal boys are more likely to develop otitis media than girls.

During 2004, the partnership:

- held the First National Workshop of the Partnership in Perth where all stakeholders attended and the three major projects were refined and structured
- made two key appointments - Partnership Leader and Partnership Manager.
- developed business plans for each of the projects - modelling the WA Aboriginal Child Health Survey, reducing alcohol and tobacco exposure in pregnancy and workforce development.

In 2004, both communities were visited to assess the health of their children. Results show that from July 2000 (before the pool was opened) to August 2004:

- skin sores in one community fell from 62 percent to 18 percent
- skin sores in the other community fell from 70 percent to 34 percent
- ear disease declined with the total number of perforations in both communities dropping from 33 percent to 20 percent.

Data from the medical centre reflects our findings, with a decline in attendance for skin and middle ear infections and reduction in the amount of antibiotics prescribed since the pool was opened.

Cheryl recently completed her PhD which explored the sense of self, identity and self-esteem of urban Aboriginal children. “I have opened Pandora’s box and am eager to continue exploring how urban Aboriginal children think and feel about themselves in the world that they live in, and how this affects their lives,” Cheryl says.

Cheryl has an amazing list of achievements to her name. As well as completing her PhD, she also has a Master of Science, a Bachelor of Applied Science and an Associate Diploma of Applied Science. She has also received numerous awards including National NAIDOC Scholar of the Year in 2001 and the Queens Trust Award for Young Australians, WA in both 1992 and 1995.

Cheryl hopes to one day become an established international researcher and author of many published papers. “My dream is to develop a centre of excellence for Aboriginal children and youth that will support and enhance their opportunities for success in their chosen achievement domains,” Cheryl says.

RESEARCH R

Asthma, allergies and respiratory diseases

	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.	Asthma is the most common chronic illness in children. In Australia, asthma affects around 30 percent of children and adolescents. All current treatments are designed to control asthma symptoms once they have developed.
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.
Allergies	An allergy is a harmful response of the immune system to a substance that is normally considered harmless. This exaggerated response is usually to indoor and outdoor allergens as well as foods. They are typically associated with diseases such as asthma, eczema and anaphylaxis. Our immune system protects us from the outside world. Sometimes, however, the system can become overprotective, launching a full-blown attack on one of those harmless substances that normally provoke little or no response.	Common allergens affecting children include: <ul style="list-style-type: none"> • grass pollen • house dust mite • cats and dogs • certain foods. The incidence of food allergies has doubled in the past decade. The most common food allergies in children are milk, egg, soy, sesame, peanuts and tree nuts. 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.



Researcher Profile

Dr Siobhain Brennan

Program Coordinator, Cystic fibrosis research

Siobhain Brennan really enjoys being able to talk to members of the local cystic fibrosis community. Having moved from 'basic' science to research with more of a clinical aspect - where she could see research being translated into practice - it is not surprising that Siobhain likes meeting families and sharing her knowledge with them.

At the Institute, Siobhain coordinates a small team of researchers who are working on cystic fibrosis, the most common genetic condition affecting Australian children. In this role, Siobhain supervises laboratory staff and students, writes new research grants and writes publications resulting from the data.

Even though cystic fibrosis research is an area Siobhain has been involved with for some time, it is something she is still passionate about. "I'm passionate about improving outcomes for young children with cystic fibrosis and their families," Siobhain says. "Having personal experience of the effects of lung disease also helps to motivate me."



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

Our research

The Institute is recognised as a world leader in research for the prevention and treatment of asthma. We are focussing on how asthma develops, better ways to manage and monitor asthma and new treatments.

Asthma results from a complex interaction between people's genes and their environment. Our research in the area of asthma includes:

- discovering a new concept for immunological defense in neonates. The immune system in newborns contains large numbers of a special type of short-lived lymphocytes, which responds to a broad spectrum of environmental antigens, without the necessity of being "immunised". This cell provides rapid short bursts of cytokines which can help in repelling invading viruses or bacteria.
- work on house dust mites and how they trigger asthma. House dust mite allergy results from an immune response to a complex mixture of proteins produced by the mite. We have successfully cloned allergens so we can analyse the allergic response to house dust mites. Our research into house dust mites is important given that house dust mites thrive in the warm, humid conditions we experience in WA.
- investigating cat allergies. Our researchers have discovered that people breathe in a messenger-molecule called EN-RAGE that is produced by cats to initiate their own protective immune responses. We are looking at how the long-term inhalation of molecules from animals affects immune responses in people.
- developing early intervention strategies in childhood to reduce disease susceptibility, ideally to prevent disease onset.
- investigating how we can control cell populations in the airway wall which are responsible for triggering the "late phase response" in asthma. This part of the response is largely responsible for progression from acute to chronic asthma. We are working on developing new therapeutic strategies to dampen the function of these cells in asthmatics.

In 2004, we continued our investigations in the area of early development of inflammation and infection in cystic fibrosis. We collected more than 250 lung fluid samples from 88 different children with cystic fibrosis - inflammation was evident in all samples, even in very young infants with no apparent clinical symptoms or infection.

We have developed a non-invasive urine test that measures the destruction of lung tissue. Lung damage caused by infections has the most impact on the health of a child with cystic fibrosis. Current tests to measure lung damage are not sensitive enough and are highly invasive. We continue to trial our urine test on children with cystic fibrosis and children with no history of lung disease.

We are also working on improving current treatments for cystic fibrosis and testing future therapies.

Our research on allergies includes:

- 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 T-cells from 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.
- continued work on early life events that cause allergies which is helping to shed light on the cause of atopic dermatitis. Studies on umbilical cord blood cells from babies at birth indicate that the Staphylococcus bacteria may be a key contributor to the development of atopic dermatitis.
- identification of new genes associated with allergen induced T-cell activation. These studies are employing exciting new technology developed as part of the Human Genome Program, and are starting to yield new information which will have a major impact on future research in this area.
- identification of new mechanisms responsible for tissue damage in allergy. In particular, our recent findings demonstrate that overproduction of some of the cytokines which protect against allergy development can have the reverse effect at later stages of the disease, and make symptoms worse.

Siobhain says that working with a great team that is smart, dedicated and enthusiastic makes a huge difference to the research environment. "Having a mentor that I can talk over the tough issues with has also kept me on track many times over the last decade."

Siobhain manages to juggle parenthood with research, and attributes the children-career balance to the family-friendly environment offered by the Institute. "Being a researcher and mother has only been possible with the enormous support of my family and flexibility of the Institute, in particular my Division Head, Peter Sly," Siobhain says.

Attracting funding is always an issue for researchers, so Siobhain says that every grant that she has ever received is a highlight in her research career. Her team has a developing interest in innate immunity in cystic fibrosis and Siobhain hopes that they are successful in obtaining funding to follow this new area of research.

In the meantime, Siobhain is looking at publishing some of her completed data so she can continue to inform those children and families whose lives she is trying to improve.

RESEARCH

Birth defects

	About	Facts and stats
Assisted reproductive technology research	We are examining health outcomes in children born following assisted reproductive technologies (ART).	In Western Australia, we have compared 2,106 infants born following ART between 1993 and 2000, with all spontaneously conceived infants born during the same period (177,451 babies).
Fetal Alcohol Syndrome	Fetal Alcohol Syndrome is the severe end of a spectrum of the effects of drinking alcohol during pregnancy.	Fetal Alcohol Syndrome was first identified in the 1970's. It has life-long consequences for the child including physical defects and intellectual disabilities. There is no cure for Fetal Alcohol Syndrome, but it is 100 percent preventable if alcohol is not consumed during pregnancy.
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 births in Western Australia. The <i>MECP2</i> gene has been identified as a cause of Rett syndrome. There is no cure for Rett syndrome.
Neural tube defects	Neural tube defects result from a failure of closure of the neural tube which is usually complete by the sixth week of pregnancy. Morbidity and mortality rates are very high in babies with a neural tube defect.	About one in every 1,000 babies has a neural tube defect. Spina bifida is one type of neural tube defect. The vitamin folate (folic acid) can prevent up to 70 percent of neural tube defects.



Researcher Profile

Michele Hansen

Project Officer, Study of significant adverse health outcomes in children born following assisted reproductive technologies (ART)

Michele Hansen certainly keeps herself busy. As well as working part-time at the Institute, Michele is completing her PhD and has the daily joys of being a full-time mother to her two-year-old son.

Michele manages a large record-linkage study examining health outcomes for children born following assisted reproductive technologies (ART). She is comparing the prevalence of cerebral palsy, intellectual disability, hospital admission and birth defects in infants born after assisted conception in Western Australia between 1993 and 2000 to all other WA infants born over the same period.

It's an important area of research, given that Australia has one of the world's highest rates of treating infertility by assisted conception. The wide application of assisted conception treatment in Australia, and the increased number of pregnancies achieved by these means, provides an impetus for Michele to continue to collect and analyse data.

In 2002, Michele made a discovery that provoked international interest. She found that for WA babies conceived following assisted conception, there was a two-fold increased risk of being diagnosed with a major birth defect by one year of age compared with spontaneously conceived WA infants. Publishing her first paper on this research in *The New England Journal of Medicine* has been a major highlight of Michele's research career.



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

Our research

In 2004, we conducted a systematic review and meta-analysis of all the published literature examining birth defects in infants conceived through ART compared with infants conceived spontaneously. We found that ART infants had a 30 to 40 percent increased risk of having a birth defect. These results generated national media interest and have had implications for the counselling of couples seeking ART treatment.

We have continued our analysis of hospital admission data in ART infants and we are also interested in cerebral palsy, intellectual disability and furthering our work on birth defects.

We are currently collecting national data to ascertain the number of children with Fetal Alcohol Syndrome in Australia.

We have also been collecting information from health professionals to determine their knowledge, beliefs and practices in relation to Fetal Alcohol Syndrome and alcohol consumption in pregnancy.

We continue to manage the national population-based Rett syndrome register (AussieRett), following Australians with Rett syndrome over a five-year period. This register has allowed us to make significant contributions to world knowledge on Rett syndrome. Of particular note in 2004, the study team developed protocols for the collection of video footage provided by study families. This footage gives the research team an unique opportunity to observe the daily living, behaviour, hand function and mobility of those with Rett syndrome.

We have also developed an international Rett syndrome phenotype database called InterRett. InterRett allows us to collect information from families and clinicians worldwide, with data already collected from as far as Malta, Argentina, Norway and Mexico. The unique web-based resource not only allows us to collect data but also allows families and clinicians to view information (such as hand use, gene mutations, and current functioning) in an interactive and user-friendly way.

In 2004, we contributed to a submission to Food Standards Australia and New Zealand for the mandatory fortification of food with folate. Our research has found that around one third of women took folic acid supplements around the time of conception. For the two thirds of women not taking supplements, fortified food is an important source of folate, and a way to help prevent neural tube defects.

We are also interested in the rates of neural tube defects in Aboriginal infants. Since the health promotion of folate and voluntary fortification of food, there has been a 30 percent fall in neural tube defects in Western Australia. However, there has been no reduction in rates in the Aboriginal population and now, neural tube defects in Aboriginal infants are almost twice as common compared with non-Aboriginal infants.

Michele credits the ability to do this research to WA's unique Reproductive Technology Register: "Western Australia is the only Australian State and one of only a few places in the world with a statutory register of reproductive technology," Michele says. "We can link these data to other WA population health registers to examine information on a broad range of health outcomes for assisted conception children."

Whilst Michele can't see past the end of her PhD yet, she hopes that her work will influence the information given to patients prior to commencing fertility treatment.

"I think it is very important that prospective assisted reproductive technology patients are given as much information as possible about any potential side-effects of treatment," Michele says. "They should also be informed about adverse health risks for their offspring so that they can make informed choices about their treatment options."

While even small increases in the risk of adverse health outcomes such as birth defects, low birthweight, and preterm birth may be quite worrying for some couples considering ART, Michele stresses that the majority of babies will be born healthy. "ART has brought great happiness to many thousands of infertile couples world-wide. Our goal is to contribute to research examining if and why there are increased risks of some adverse health outcomes in ART infants, for the sake of the parents and their children."



RESEARCH

Cancer and leukaemia

	About	Facts and stats
Leukaemia	<p>Leukaemia is cancer of the white blood cells and these white blood cells are produced in bone marrow.</p> <p>Our leukaemia research Division is a member of the US-based Children's Oncology Group, the world's largest study group into childhood cancers.</p>	<p>Leukaemia is the most common form of cancer in children, accounting for around one third of all cases.</p> <p>Leukaemia affects around one in every 2,000 children in Australia.</p> <p>It is more common in boys than girls with a 1.4 to 1 ratio.</p> <p>There is a peak incidence in patients aged between two and four years.</p> <p>Survival rates have increased to more than 70 percent.</p>
Brain tumours	<p>We are interested in primitive neuroectodermal tumours (PNETs), the most common type of brain tumour affecting children.</p>	<p>Brain tumours are the second most common form of cancer in children.</p> <p>Survival rates are between 50 and 70 percent.</p>
Skin cancer	<p>Skin cancer is predominantly caused by overexposure to the sun's ultraviolet radiation.</p> <p>We are interested in basal cell carcinoma, the most common type of skin cancer, which is one type of non-melanoma skin cancer.</p> <p>Our research also focuses on melanoma.</p>	<p>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.</p> <p>Basal cell carcinoma accounts for around 70-85 percent of all skin cancers.</p> <p>Melanoma is the most serious of all skin cancers but is less common, accounting for around 5 percent of all skin cancer cases.</p>



Researcher Profile

Dr Peter Dallas

Senior Research Officer, childhood brain tumours

Peter Dallas loves surfing, camping, fishing and boating, so it's probably a good thing he's chosen to call Perth home. In fact, he is passionate about everything Western Australian, especially our beautiful coastline. But he is equally passionate about his research into childhood brain tumours.

Peter joined the Institute in 1999 after spending five years at the Fels Institute for Cancer Research in Philadelphia in the United States following the completion of his PhD.

Being the first to clone and sequence the p270 gene – which encodes a protein which is involved in modifying the structure of DNA – at the Fels Institute has been a highlight of Peter's research career, particularly given that two other laboratories were also trying to clone the gene.

Now, Peter heads a small team of scientists investigating the molecular biology of primitive neuroectodermal tumours or PNETs, the most common type of brain tumour affecting children.

Whilst brain tumours are quite rare, the disease is one that Peter feels strongly about. "The concept of a brain tumour is particularly scary, especially for children and parents," Peter says. "PNETs are aggressive and still kill a significant percentage of patients and unfortunately, survivors face the possibility of intellectual impairment and disability associated with brain surgery and chemotherapy or radiotherapy."



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

Our research

Our research focuses on the genetic events leading to leukaemia in children and on developing more specific and less toxic anti-cancer drugs. We are using the novel microarray technology (which allows us to look at more than 20,000 genes at the same time) to identify the critical genetic events that lead to cancer. Our researchers are investigating the genetic differences among subtypes of cancer cells and normal cells and this knowledge will form the basis of better diagnostic tests, classification and ultimately treatment of leukaemia.

We use our panel of established cancer cell lines to test potential new drugs for the treatment of leukaemia in children. These cells lines are essential for our work in developing better cancer therapies, not only to identify new drugs but to also measure their effectiveness. Our unique ability to “grow” cancer cells in the laboratory is vital for our ongoing cancer research.

We are studying the SCL gene which is a major trigger of T-cell leukaemia and are also discovering new genes responsible for causing this disease. The SCL gene is critically important for blood cell generation. It also occurs in the central nervous system and we are trying to determine whether it is also important for brain development.

We are also leading a national epidemiological study into the causes of childhood leukaemia - the Australian Acute Lymphoblastic Leukaemia (AUS-ALL) Study. An Australia-wide team of researchers and doctors is working together to identify possible genetic, dietary and environmental causes of the disease. This information will help us to understand why leukaemia develops and how it may be prevented. The study is recruiting 350 children aged up to 14 years with leukaemia and a control group of 700 children, matched by age, gender and State of residence. This study has completed its second year, with the continued recruitment of children both with leukaemia and without, and the collection of questionnaires and DNA samples.

Our research is looking at the molecular biology of PNETs to identify changes that have occurred at the basic genetic level in tumour cells. We know that chromosomal abnormalities are a common feature of PNET cells, and the challenge is to identify the genes that are deregulated by these chromosomal rearrangements. Our research team is using microarray technology to achieve this goal.

Several genes of interest have been identified using this approach, and we are testing the effects of deregulated expression of these genes in a neural stem cell model of brain tumour development. The aim is to gain a better understanding of the molecular biology of brain tumours so we can develop more effective treatments that are urgently required.

We are investigating the molecular links between sun exposure early in life and skin cancer development, for both melanoma and the more common basal cell carcinoma.

Ultraviolet radiation penetrates only the first few millimetres of skin, yet its effects on our immune systems can be widespread in the body. We are therefore interested in the critical events initiated in the outermost layers of skin.

Both the chemical and the cellular components are important.

In Australia, research on the molecular biology of childhood brain tumours has been limited so Peter's team is poised to make a significant contribution to the research community's understanding and knowledge of this cancer:

“We desperately need more effective and less invasive treatment options for kids with brain tumours. This is where our project can make a contribution,” Peter says.

Peter and his team continue to search for those critical brain tumour genes and are trying to secure funding for the next few years to incorporate a neural stem cell model into their research.

In the long-term, Peter would like to develop a productive, enthusiastic and securely funded brain tumour research lab. “I've managed to survive this long in science and I would like to have my own lab one day – preferably before I go completely bald!”



RESEARCH

Developmental disorders

	About	Facts and stats
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 result in partial paralysis, lack of limb coordination, epilepsy and defects in posture, intellect, vision, hearing and speech.	Cerebral palsy is the most common physical disability in children. There is no cure for cerebral palsy.
Intellectual disability	About 350 children are born with an intellectual disability each year in WA. The cause is unknown, in about half of the cases.	Down syndrome is the most common type of intellectual disability. There are also many rare conditions that affect a small number of children.
Newborn encephalopathy	Newborn encephalopathy is a clinically defined syndrome of disturbed neurological functioning (abnormal brain activity) in the earliest days of life in a full-term infant. This underlying abnormal brain activity may result in a baby that has problems breathing, feeding, has poor tone and reflexes and sometimes they may also have seizures, inevitably affecting the child's growth and development.	Newborn encephalopathy (NE) occurs in around one in every 300 births. Of the infants with NE in our study: <ul style="list-style-type: none"> • 13 percent have died • 12 percent have cerebral palsy • 30 percent have a disability.
Obesity	A potentially major health problem which continues throughout adulthood, obesity increases the risk of high blood pressure and cholesterol levels, heart disease and type two diabetes.	Australian-wide data suggests that 19 to 23 percent 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, they have a specific problem in understanding and expressing themselves with language.	SLI currently affects approximately seven percent of WA single-born children with otherwise normal development. The rate of SLI in twins is not known.



Researcher Profile

Glenys Dixon

Project Manager/Psychologist, West Australian newborn encephalopathy study

Glenys Dixon has come a long way since her days serving tea in the banking industry. She's been a bank teller, had two children, worked as a teacher's aide and completed university as a mature age student. Today, Glenys is a registered psychologist and manager of the internationally unique newborn encephalopathy study, and a testimony that if you work hard and stick at it, you can achieve your dreams.

Newborn encephalopathy is a term most people wouldn't have heard – unless it's struck their own family. It's used to describe the heartbreaking scenario when a full-term baby has serious and unexpected problems in the days after birth, such as fits or breathing difficulties. Having watched many of the study children develop for more than eight years, Glenys has an amazing rapport with the study families and understands the value of this work.

Glenys first began working on the newborn encephalopathy study in June 1996, working two days a week assessing children after completing her first degree. She says the longer she worked on the study, the more she felt an affinity and admiration for the people she was working with.



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

Our research

Our research into cerebral palsy has shown that less than ten percent of cases are due to problems during labour - infections during pregnancy and preterm births play a more significant role.

At the Institute we house the Western Australian Cerebral Palsy Register which collects data to monitor trends in cerebral palsy overall and in groups such as preterm or multiple births, and to facilitate studies into the causes of cerebral palsy.

In 2004, we have continued to coordinate the planning of the Australian Cerebral Palsy Register, which will monitor and ascertain all cases of cerebral palsy in Australia. This register will enable more powerful research not currently possible with the small numbers on individual State registers.

The new Intellectual Disability Exploring Answers database (IDEA) combines data from the WA Disability Services Commission and the Department of Education and Training.

Children with intellectual disabilities have more substantial medical needs than children without. This leads to higher risk of hospitalisation in the first five years of their life mainly for infections and respiratory disease.

We have been using the database to investigate the social determinants of intellectual disability and found children born to Aboriginal, teenage, and single mothers are at increased risk of intellectual disability. Mothers who are socio-economically disadvantaged are at greater risk of having children with mild to moderate intellectual disability.

Our research began in 1993 and has involved 276 infants with newborn encephalopathy and 564 healthy full-term infants born in WA between June 1993 and December 1996. This study is tracking the long-term outcomes for these children in an effort to determine how NE will affect the quality of life for these children.

We have shown that the causes of newborn encephalopathy are diverse and many of these start during the pregnancy, with only ten percent due to birth asphyxia. We have identified risk factors for NE such as a family history of seizures, infertility treatment, increasing maternal age and maternal thyroid disease.

Follow-up research has shown a previously undescribed association between NE and autism, with infants with NE being six times more likely to have an autism spectrum disorder.

Our research aims to identify the biopsychosocial factors that contribute to the development of childhood obesity and the factors affecting the development and persistence of eating and weight problems. We are also interested in strategies and protective factors that can prevent children from becoming obese.

We are following three groups of children and their families, assessing biological, psychological and social environments as well as diet to determine what influences childhood obesity. Children and their parent(s) are assessed upon enrolment and at six-monthly intervals for at least three years. Assessments include the collection of height and weight data, and measures of a broad range of biological, psychological and social/environmental factors that are suggested to influence the persistence of childhood obesity into adolescence and adulthood.

Our LOOKING at Language study aims to understand more about genetic and environmental factors that influence language acquisition and Specific Language Impairment in twins and single born children during their toddler, preschool and school years.

We are collecting valuable evidence from a population-based sample of WA families with children aged between one and eight years to identify children who have SLI. There are currently almost 2,000 children involved in the study and over 1,000 children and their family members have taken part in our assessments of language and related abilities.

"It was therefore a natural progression to focus on this particular area of research. However, upon reflection, I think any research into issues relating to child health would gain my attention and be equally as easy to focus upon," Glenys says.

A key achievement for Glenys was forcing herself out of her comfort zone and into new and unfamiliar roles, such as study and a developing career: "To continue to develop and learn no matter what my age also gives me a sense of achievement and satisfaction and I feel lucky to have had the opportunity to follow my dreams," Glenys says.

"I am passionate about making a difference to the lives of others - this translates to an immense passion for my work and also for the Institute. I want to continue to make a difference in whatever way I can."

Glenys says that when families and teachers have taken the time to pass on their thanks for the research work and advocacy, it fuels her passion for her work. "It really keeps me going in the times that are more challenging personally and career-wise," Glenys says. "I am also lucky enough to be surrounded by people dedicated to the same passions as I have so it is relatively easy to keep working in the research field."

Despite funding troubles for the study, Glenys is determined to continue to analyse and publish the data and results that have amassed over the years. "The information we have collected is largely thanks to the generous participation of the many families involved. To not continue would be negligent," Glenys says.

With her obvious passion for research and child health, Glenys is now looking to the future and hopes to begin a PhD very soon - so she can ensure that the results from the study are published and widely disseminated!

RESEARCH

Infectious diseases

	About	Facts and stats
Vaccine trials	<p>Effective vaccines reduce the frequency and severity of disease for individuals and reduce the overall cost of health care.</p> <p>Our Vaccine Trials Group provides a coordinated approach to developing, delivering, assessing and promoting vaccines and allergy treatments in our community.</p>	<p>The Vaccine Trials Group was established in 1999, a collaborative venture between the Institute, Princess Margaret Hospital for Children and the School of Paediatrics and Child Health at The University of WA.</p> <p>We have been involved in many international multi-centre studies with paediatric and adult vaccines.</p>
Pneumococcal disease	<p>The pneumococcus is a bacterium (also called <i>Streptococcus pneumoniae</i>) that causes meningitis, pneumonia (inflammation in the lungs), septicaemia (blood poisoning) and severe ear infections.</p> <p>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 from the respiratory tract and through close personal contact. Many people naturally carry the bacteria in the back of their nose but few become ill.</p>	<p>Throughout the world an estimated one million children die annually from pneumococcal disease, the majority being in early infancy.</p> <p>In 2004, there were 199 reported cases of invasive pneumococcal disease and 21 deaths in WA. 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 than non-Aboriginal and Torres Strait Islanders.</p>
Meningitis	<p>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.</p>	<p>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.</p> <p>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.</p> <p>Fungal meningitis is a very rare, life threatening disease and may be caused by a variety of fungi.</p>
Encephalitis	<p>Murray Valley encephalitis (MVE) and Japanese encephalitis are potentially fatal mosquito-borne diseases of the Asia-Pacific region.</p>	<p>MVE is also known as Australian Encephalitis.</p> <p>This form of encephalitis results from an infection with MVE virus or Kunjin virus</p> <p>Since 1974, cases of MVE have occurred sporadically in Northern Australia and in the north west of WA.</p>
Enterovirus 71	<p>Enterovirus 71 is a gastrointestinal virus that can cause paralysis in toddlers. Symptoms of enterovirus 71 are often flu-like but in rare cases, complications can severely affect the brain.</p>	<p>Large epidemics of enterovirus 71 have occurred in Australia and South-East Asia since 1997.</p> <p>Severe neurological disease has resulted in numerous cases, including in Perth, Western Australia.</p>



Researcher Profile

Clinical Associate Professor Deborah Lehmann

Senior Research Fellow, Investigation of causal pathways to otitis media (middle ear infections) in Aboriginal and non-Aboriginal children

Deborah Lehmann is a big picture person. Her focus on tackling the common infections that afflict the most disadvantaged children – in the developing world and here in Australia – means that her work makes a difference on a massive scale. She is driven by a personal commitment to improving the health of underprivileged children.

Infectious diseases don't capture the headlines like they once did – thanks mainly to effective vaccination campaigns. But what people like Deborah Lehmann don't forget, is that infectious diseases are still the biggest cause of death and disability in children.

Recognised internationally for her expertise in the epidemiology of acute respiratory infections and pneumococcal vaccines, Deborah's focus throughout her career has been on improving the health of the most disadvantaged people. She's worked in Tuberculosis control in Nepal and spent 17 years in Papua New Guinea, where she ran big studies on acute respiratory tract infections and



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

Our research

In 2004 we began several new vaccine trials including:

- a Human Papilloma Virus (HPV) vaccine with the potential to prevent cervical cancer. HPV is a virus that infects the skin and cervix. Chronic HPV infections are the main cause of cervical cancer in women. Currently there is no proven way of preventing infection with HPV.
- a study for children aged from six months to eight years which will examine the effectiveness of an Australian influenza vaccine in children. Some children who get influenza will develop serious complications such as croup, bronchitis, middle ear infections, pneumonia and inflammation of the heart and brain. Flu vaccines have proved to be successful in children from other countries and are important given that children often pass influenza infection onto other high risk groups such as their elderly grandparents.
- the combined meningitis vaccine (see below).

Our research into pneumococcal disease includes:

- working with the Papua New Guinea Institute of Medical Research, to undertake a study to immunise newborns in Papua New Guinea with pneumococcal conjugate vaccine. The aim of the study is to reduce high death rates associated with acute respiratory infections caused by pneumococci in the first year of life. Other pneumococcal vaccines have proven effective in reducing early onset of dense respiratory tract bacterial carriage when given from the age of six months onwards to children in Papua New Guinea. Around 35 percent of deaths in Papua New Guinean children under five years of age are due to respiratory tract infections, with infections accounting for around 50 percent of deaths in children less than 12 months old.
- testing the effectiveness of a pneumococcal vaccine against acute ear infections (otitis media). Acute ear infections are one of the most common childhood illnesses with almost all children suffering at least one episode before the age of three years. One in six children will suffer from recurrent ear infections, which may result in hearing problems as well as affect their speech development and behaviour. The most common germ to cause ear infections in young children is the pneumococcal germ, of which there are several types. We are trialling the Prevenar vaccine to see if it will be effective in reducing ear infections in children who are known to suffer from recurrent ear infections.
- monitoring cases of invasive pneumococcal disease including collecting clinical, risk factor and microbiological data for all cases across Western Australia. We are also monitoring the effectiveness of two pneumococcal vaccines, Prevenar and Pneumovax, which were recently added to the routine immunisation schedule.

We are trialling a combined meningitis vaccine to determine the effectiveness of a new combination vaccine against Haemophilus Influenzae type B and Meningococcal C and Y infections. In order to decrease the number of injections that babies need in the first 6 months of life, combination vaccines are being developed. This combination vaccine is given with a child's routine vaccinations including the chicken pox vaccine.

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

We are:

- conducting molecular genetic studies of Murray Valley encephalitis virulence determinants using an infectious cDNA clone of MVE virus developed in our laboratory
- looking at virus-host interactions that lead to encephalitis and host determinants of susceptibility to infection.

In collaboration with research groups in Taiwan, Vietnam and Malaysia, we are studying the molecular epidemiology and genetics of virulence of enterovirus 71 in the region. Our ultimate aim is to develop a genetically defined, live-attenuated vaccine.

We are also involved in a five year international collaboration to train scientists from the Asia-Pacific, such as Vietnam, Indonesia and Sarawak Malaysia, in molecular methods of enterovirus 71 surveillance. After five years we hope to have a greater understanding of enterovirus 71 throughout those countries affected by this disease.

trials of vaccines to prevent the potentially devastating Hib and pneumococcal infections.

It's work that she's continued since joining the Institute in 1998.

"I'm interested in better understanding the epidemiology of infectious diseases, in particular respiratory infections, and of course, the proper evaluation of interventions," she says.

"We have to reduce the enormous burden of infectious diseases worldwide – and that can only be achieved through targeted and co-ordinated multidisciplinary research, like what we can achieve here at the Institute."

The health burden faced by Aboriginal children is a major concern. Deborah leads a team investigating the pathways to otitis media (ear infections) in Aboriginal and non-Aboriginal children in the Kalgoorlie-Boulder area where they've been monitoring children from birth to age 2 years.

"Otitis media is an example of a common infection that can have a profound life-long impact on a child. If their infections aren't treated, they can suffer severe hearing loss that will affect their language development, education, socialisation and employment."

Deborah is also committed to training the next generation of researchers and is key person in the Indigenous Capacity Building Grant just awarded to the Institute.

She'll be doing more work on analysing causes of otitis media, will be starting a neonatal pneumococcal immunisation trial and will use WA's unique linked data bases to look at hospitalisation due to infectious diseases.

When Deborah does find time to relax she enjoys playing chamber music, walking, running and reading. But she concedes that her biggest challenge is juggling all her research projects.

RESEARCH

Mental health

	About	Facts and stats
Suicide prevention research	The Ministerial Council for Suicide Prevention (MCSP) advises government and coordinates a range of statewide activities aimed at reducing the morbidity and mortality associated with self-harm and suicide.	Australia has a rate of youth suicide which is in the top third of developed countries. Mental health problems affect a growing proportion of our young people with an increase in problems such as Attention Deficit Hyperactivity Disorder (ADHD), behavioural disorders, depression and substance abuse.
Bereavement pack	An information and support pack aimed at assisting those bereaved by suicide or other sudden death.	The pack is available on the MCSP website at www.mcsp.org.au The pack is funded by the National Suicide Prevention Strategy
Australian Suicide Prevention information and 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.	Provides access to over 3,000 research articles and resources. ASPiRE is located on the MCSP website at www.mcsp.org.au Supported by Woodside Energy Limited.
Gatekeeper suicide prevention training	The Gatekeeper training provides participants with a range of skills and knowledge that aims to improve their ability and confidence to work with suicidal people. Primarily, participants learn how to identify and respond to people who are at risk of suicide.	In 2004, over 700 people in WA attended Gatekeeper training, which is provided by the Ministerial Council for Suicide Prevention. The regional trainer network consists of 80 accredited and trainee Trainers.



Researcher Profile

Bronwyn Williams

Executive Officer, Ministerial Council for Suicide Prevention

Bronwyn Williams says the most difficult thing about her research is knowing when to stop. As a key member of the Institute's suicide prevention research team, Bronwyn knows first hand how one answer can generate a thousand questions.

Bronwyn has been working in the suicide prevention field for about ten years. She recently completed her Masters in Clinical Psychology and for her thesis, evaluated the suicide prevention training program that the Ministerial Council for Suicide Prevention has been running for the last 14 years.

"I compared trained participants with their non-trained peers and found that training did indeed adjust participants' beliefs about suicide and suicide prevention," Bronwyn says.

"We knew anecdotally that participants had always found the training to be really helpful and could often see attitudinal change in participants. But we really needed some hard evidence to back that up, to know that the training was having a positive impact, and this research provided that evidence."

In Western Australia, mental health disorders are a leading cause of disease burden - particularly depression which is strongly linked to suicide - and suicide is a leading cause of death in younger age groups. Bronwyn says these issues don't have the high profile of other health concerns, but the impact is very real for any community caring for people at risk.



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 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.

We have also conducted research into the prevention, treatment and support needs of suicidal males aged 17 to 35 years. A total of 591 participants from the general population, at risk groups, carers and service providers were involved. Internationally unique data has been collected on suicidal men's knowledge, attitudes and behaviours in relation to help seeking and service and support access. We are hoping to use the findings to inform universal strategies as well as initiating changes to current community based treatment services to make them more accessible and appropriate to men's needs.

We developed this key resource based on research on the information and support needs of families bereaved through suicide. The pack is distributed through the Coronial counselling service to all families bereaved by suicide or other sudden death. It is also available online at www.mcsp.org.au

We have evaluated the pack to ascertain its usefulness and perceived relevance, with strong support for the pack by bereaved family members and friends. The majority (75 percent) reported finding it very helpful during their bereavement. This indicates a need for on-going distribution of such an information and support pack to those bereaved by suicide.

ASPIRE not only allows for the dissemination of information, but also translates research from the MCSP into resources and training for service providers and communities.

In 2004, the publication 'Using the Internet for Suicide Prevention' was published, based on research conducted by the MCSP. The guide seeks to assist community members and professionals in accessing safe, accurate and appropriate suicide prevention information, counselling and chat rooms on the Internet.

The workshop includes an overview of suicide, risk and protective factors, warning signs, mental disorder, risk assessment, intervention for low, medium and high risk, self-harm and postvention. Participants receive extensive resource material as well as the opportunity to develop local strategies to address suicide.

In 2004, we looked at the implicit theories about suicide causes, risk behaviours and prevention strategies of participants of the Gatekeeper workshop and whether or not training alters these beliefs. The study found that following training, and when compared to a group of non-trained peers, participants' implicit theories changed on a number of dimensions, including increased endorsement of social isolation as a cause of suicide, several signs of suicidal behaviour including preparation for dying, and the benefits of proactive interventions and social support as suicide prevention.

Bronwyn is keen to see an across-government approach to suicide prevention in WA. "Our state leads the country in suicide prevention research and the Council is regarded as one of the best systems for coordinating suicide prevention initiatives," Bronwyn says. "Since suicide is multi-causal, prevention needs to be multi-modal. I'd very much like to see the work of the Council consolidated by all WA government departments so we can develop a considered plan that will support communities."

Bronwyn says that suicide prevention, contrary to popular belief, is a very hopeful field. "It's essentially about promoting community and human connection and everyone is qualified to do that."

Bronwyn plans to commence her PhD in the near future, something she hopes to finish before she retires! In the meantime, she is thrilled to be working with a team of world-class researchers and hopes her work can make a difference. She's also planning her wedding – a full time job in its own right!

For more information about the Ministerial Council for Suicide Prevention visit www.mcsp.org.au



RESEARCH

Perinatal epidemiology

This research focuses on understanding the early factors in children's lives that may later impact on their health or the development of disease.

	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 live-born children have been followed at birth, one, two, three, five, eight, ten, and now 13 years of age.	The study is one of the most extensive surveys of pregnancy and early childhood to be carried out anywhere in the world. The Raine Study represents a collaboration between researchers from the Institute, the Women and Infants' Research Foundation, 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 well-being throughout life.
RASCALS Study	The RASCALS study is a ten percent random sample of WA mothers who had a baby between January 1995 and June 1997. The study is interested in their behaviour before, during and after pregnancy.	One of a few key longitudinal studies in Australia. RASCALS is an acronym for Randomly Ascertained Sample of Children in Australia's Largest State. Initially, 6019 mothers were contacted to become involved in the study - 82 percent of these returned completed questionnaires.
Australian Early Development Index	The Australian Early Development Index (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. Its is building the data infrastructure for teachers to be able to complete checklists on-line to measure five areas of child development: <ul style="list-style-type: none"> • Language development • Emotional maturity • Physical health and well-being • Communication and general knowledge • Social competence. 	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 consisting of 420 schools and more than 20,000 children will be participating during this time.



Researcher Profile

Dr Garth Kendall

Postdoctoral Research Fellow, The Raine Study

For Garth Kendall there simply aren't enough hours in each day. Driven by a passion to alleviate the inequalities in children's health and development, Garth is involved in a number of major research projects. And Garth's dedication to his research, sees him throw himself fully into his work.

"I could happily sit at my desk all day, every day of the week because I'm involved in so many worthwhile projects and I'm so absorbed in my work," Garth says. "But I could certainly do with some help, someone to do administrative tasks and some of the more fundamental research tasks.

It all comes down to adequate funding in the end, I suppose."

After training as a nurse, Garth worked as a community child health nurse giving him the opportunity to work with young children in family and school settings. It was this experience that inspired him to embark on further training in Population Health and to undertake research that seeks to improve the health and development of children who are disadvantaged because of their socioeconomic status, culture, or ethnicity.

"We have a responsibility to give every child, in every family, in every community the best possible start in life," Garth says. "All children are important, no one more so than another: How can humanity possibly justify the neglect of so many children when we live at a time of unprecedented wealth? Is this modernity's paradox?"



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

Our research

The Raine Study is a multi-faceted collection of data regarding a broad range of aspects of child health and development.

The Study began in the late 1980s when almost 3,000 women were enrolled at between 16 and 20 weeks in pregnancy through the antenatal booking clinics at King Edward Memorial Hospital. The children have been followed at birth, 1, 2, 3, 5, 8, 10, and now 13 years of age. The investigators remain in contact with 2,300 families and most continue to contribute to the study by completing questionnaires and attending assessments at the Institute.

In 2004, data collection included measures of physical activity, physical fitness, motor competence, nutrition, posture, joint mobility, back muscle strength, blood pressure, respiratory function, allergy, and stress responsiveness. In addition, information was collected regarding child 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.

Specific areas of interest include: the psychosocial determinants of child health and development, growth, nutrition, the metabolic syndrome, physical activity, obesity, musculo-skeletal development, asthma and allergy, and stress responsiveness.

The RASCALS study team continues to follow a portion of these mothers on an annual basis. Families are contacted each year at the time of their child's birth. Initially, information was collected on rubella immunisation, folic acid intake, SIDS risk factors, infant feeding practices, cigarette smoking, alcohol consumption, infertility, family composition, and so on. Subsequent questionnaires have asked mothers for information on parenting and disciplinary practices, parents' employment, stress and mental wellbeing of the child and parent.

Data collected by the RASCALS study is being used in a variety of ways including assessing sleep patterns, dental visits and information and communications technology exposure. Some children from the RASCALS study are also involved in our LOOKING at Language study.

In 2004, the first Australian sites were selected to complete the AEDI - Kalgoorlie, Carnarvon, Gosnells, east metropolitan Perth, and Mirrabooka in Western Australia; East Gippsland in Victoria; and the Gold Coast in Queensland. Just over 6,000 children from these communities participated in the first round to test and facilitate the use of the AEDI across Australia.

The results from the AEDI will provide communities with a basis for reviewing the services, supports and environments that influence children in their first five years of life. It also provides information for schools and the community to look ahead to the supports that need to be developed to enhance children's capacity to be successful once they reach school.

The project developed a secure, web-based data entry system for teachers to complete the AEDI checklists. The innovative system enabled data to be checked and downloaded at any time, and reduced the costs associated with paper and data entry. A total of 96 percent of teachers found the web-based data entry system easy to use.

Today, amongst other things, Garth is the Executive Officer of the Western Australian Pregnancy Cohort (Raine) Study which is following over 2,000 young people and their families from before birth to adulthood.

"We have been following the lives of these children and their families for more than 14 years and have collected extensive demographic, psychological, health and developmental information," Garth says. "I am proud to be part of a study now regarded as one of the most comprehensive studies of child health and development to be conducted anywhere in the world."

In 2004, Garth completed his PhD, both a personal and professional achievement for him. In the near future, he hopes to continue to publish papers from his PhD research and become a fully-fledged NHMRC Research Fellow.

Although he has many plans for future research, Garth understands that everyone needs to have a balance in life between work and time off. A past marathon runner, skier and mountaineer; most of Garth's spare time is now taken up with activities that involve his wife and two teenage children. "We enjoy walking, cycling, swimming, snorkeling and playing tennis together; nothing too strenuous or competitive," Garth says. Occasionally he goes windsurfing out on the ocean on his slalom board. "I must admit that the idea of being bitten by a shark doesn't appeal, and the recent publicity has put me off a bit."

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 inception. 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.



Heather D'Antoine

Manager Kulunga Research Network until July 2004

Heather joined the Institute in 2001 as the manager for the Kulunga Research Network. Heather has extensive experience in health service delivery and was employed as the Health Service Manager for Fitzroy Crossing and Halls Creek prior to joining the Institute.



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



Prue Hart

BSc(Hons) MSc PhD

Head of Inflammation Laboratory

Principal Research Fellow, NHMRC and an Adjunct Associate Professor at the University of Western Australia. She 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

Manager, Kulunga Research Network

Associate Professor, Curtin University, Colleen was recently recruited from the Aboriginal and Torres Strait Islander Services agency of the Australian Government. Colleen is a senior Noongar woman with family ties throughout the south-west of Western Australia. She has an extensive policy and management background in a range of 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 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

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.



Ursula Kees

Dip Phil II PhD

Head of Division of Children's 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

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.



Peter McMinn

BMed Sc (Hon) MBBS PhD FRCPA FRCPath DipRACOG

Head of Division of Virology

Peter McMinn is a virologist who joined the Institute in 2000. He is an inaugural holder of an NHMRC Practitioner Fellowship and is 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 microbiologist at Princess Margaret Hospital for Children.



Sven Silburn

BSc(Hons) MSc (Clin Psych) MAPS

Senior researcher, Population Sciences

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, Department of Paediatrics, 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 the Walter and Eliza Hall 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 holds a Professorship in the Institute and Curtin University of Technology's Centre for Developmental Health. He was previously head of the Institute's Division of Psychosocial Research and has worked in various mental health settings. He chairs the Consortium Advisory Group, National Longitudinal Study of Australian Children and sits on the Commonwealth Mental Health Promotion, Prevention and Early Intervention Working Party.



Collaborations and joint ventures

UWA Centre for Child Health Research

This Centre was established in 2001 with an agreement between The University of Western Australia and the Institute. The Centre facilitates closer collaboration with the University, providing access for clinical and adjunct academic 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 and Dentistry, and is closely linked with the School of Paediatrics and Child Health, which is based at Princess Margaret Hospital for Children and located adjacent to the Institute. 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 due for renewal in 2006. This will provide the opportunity to reassess the value of this mutually beneficial strategic alliance. This and other university centre agreements with the Institute will be included in the terms of reference for the next quinquennial review of the Institute in 2006.

Curtin Centre for Developmental Health

The Centre for Developmental Health is a joint venture between the Institute and Curtin University of Technology. Established in June 2001, the Centre has brought 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.

Over the past three years the Centre has developed a national and international profile in academic research and policy, establishing strong links with government and other agencies responsible for the health, education and wellbeing of children in Western Australia, and Australia. In the first three years of operation the Centre's researchers successfully competed for grants totalling almost \$8 million dollars.

During 2004 the Centre helped establish Australia's first post-graduate course in developmental health through the Curtin School of Nursing and the Division of Health Sciences.

Collaboration for Applied Research and Evaluation

The Collaboration manages a range of projects through contracts with the WA Department of Health and other agencies. These collaborations are aimed at providing the foundation to improving child, youth and family health and wellbeing outcomes in this State in years to come. This is delivered through population health initiatives (such as those to reduce preventable disease, injury, disability and premature death) which are based upon the Institute's research findings and track record for informing policy and health care practice and service delivery.

The ongoing collaborative partnership between the Institute and the Department of Health is expected to produce policy and practice relevant outcomes through the dissemination and application of information and research knowledge, and through expert advice and consultation from the State's leading researchers in child health.



Corporate partnerships

The Institute would like to acknowledge and thank our corporate partners for their ongoing and significant support to our research program. Each partnership brings a unique opportunity to engage the corporate community, their stakeholders and staff in our cutting edge research and by working together we are better able to improve the health and wellbeing of children and their families.

The Institute is proud of the continued support of the Western Australian people, through Channel Seven's Telethon. This commitment is vital for our ongoing success.

Our partnership with Shell Australia supports the Australian Early Development Index: Building Better Communities for Children project. This is a national project in partnership with the Centre for Community Child Health and will help up to 60 communities throughout Australia understand how their children are developing by the time they reach school age.

The Rio Tinto Child Health Partnership is a unique partnership with state, territory and federal governments, Rio Tinto and the Alcohol Education and Rehabilitation Foundation to improve the health and wellbeing of Aboriginal and Torres Strait Islander children.

We are proud to announce a new three year partnership with Alcoa. The Alcoa Child Health Partnership will strengthen the capacity of Professor Fiona Stanley and her team in research and advocacy, to improve the future health and wellbeing of Australia's children.

The Young Investigator of the Year Award is supported by QANTAS Airways Limited. The QANTAS partnership also provides the Institute the capacity to build collaborations and share scientific knowledge and expertise.

The Institute is proud to announce the Stan & Jean Perron Fellowships. Through the generous support of the Perron Foundation, the Institute is now able to offer a range of scholarships to attract the most talented and brightest researchers.

HBF has enabled a unique Childhood Growth and Development Study to investigate growing concerns regarding the increase in childhood obesity.

Woodside Energy Limited has continued its support for the Ministerial Council for Suicide Prevention: resource and information strategy that aims to provide the community with informative and effective resources to aid in the prevention of suicide.

KPMG provides valuable advice and continued support for our research.

Wesfarmers Limited continues to provide important support to our research program and as an acknowledgement of this commitment to child health in Australia, our Atrium carries the Wesfarmers name.

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



Researcher Profile

Dr Graeme Zosky

Research Officer, Study of asthma and wheeze following respiratory infection

Graeme Zosky is driven by a need to understand how things work. His curiosity, coupled with a passion for high quality research, has seen him excel in his relatively short research career. His research excellence has been recognised by a number of awards including the 2004 QANTAS Young Investigator Award.

Graeme joined the Institute in August 2003 after completing a PhD in Zoology. His research focuses on the impact of disease on lung function. Graeme is interested in how lung disease alters airway smooth muscle and how this causes the 'wheeze' and difficulty in breathing that is characteristic of childhood diseases such as asthma.

"The majority of my work involves measuring lung function in animal models of allergic airways disease as part of a larger collaborative project that aims to understand the pathobiology of asthma," Graeme says.

Affiliated groups' reports

The Meningitis Centre

2004 was another exceptional year for The Meningitis Centre. Expectations were surpassed, as the Centre became Australia's only source of information and awareness for all forms of meningitis.

The Centre's major achievement was the success of "Operation Free Pneumo" after years of campaigning and lobbying the Federal Government. Pneumococcal immunisation finally received funding and inclusion in the National Immunisation Schedule starting from January 1, 2005. Infants will receive immunisation at two, four and six months while seniors over 65 are also eligible for free pneumococcal vaccine.

Other highlights for 2004 included:

- Chairman Bruce Langoulant represented Australia at the first World Conference of Meningitis Organisations. The Confederation of Meningitis Organisations was formed including fifteen member organisations from twelve countries.
- The Peer Support Program took its first steps towards formalisation, with the introduction of policies and training for the first group of parents and trainers.
- Our website www.meningitis.com.au received a complete make over - it is now very user friendly and contains much more information. The site was visited over 28,000 times and we received over 2,000 freecall inquiries.
- A book based on personal experiences of families whose lives have been impacted by meningitis has been commissioned and being written by medical writer Joanne Fowler.

Louisa Alessandri Memorial Fund

The Louisa Alessandri Memorial Fund 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.

The Louisa Alessandri Scholarship is awarded annually to a tertiary student with a disability. The 2003/2004 Scholarship was awarded to Katie Ellis, a PhD candidate in Communication Studies at Murdoch University. Two exceptional applicants Benjamin Rowe and Cameron Worts were presented with Achievement Awards.

The annual oration was presented by Professor Linda Kristjanson, the Cancer Council of WA Chair of Palliative Care and Associate Dean of Research and Higher Degrees, Faculty of Computing Health and Science at Edith Cowan University. Her thought-provoking address was titled "The Impact of Illness on the Family: Bolstering the Hidden Carers".

The recipient for the Louisa Alessandri Award for Excellence and Commitment in Research was Lee Hazell of the Molecular Biotechnology Laboratory. This award recognises a person who promotes excellence in research through dedication to their work and colleagues.

Friends of the Institute for Child Health Research

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 also provide financial assistance to a range of research projects.

In 2004, the Friends held a cocktail evening at the Institute, a preview screening of the film Evelyn, a Christmas brunch, again at the Institute, and their successful annual ladies golf day at Cottesloe Golf Club.

These events allowed them to provide funding for flights, accommodation and conference registration for a number of Institute staff and students as well as fridge magnets, videos and bean bags for Institute studies.

The Margaret River Friends continue to receive great support from the Margaret River community. They have completed their funding of the Margaret River Marijuana Education project and are looking forward to funding new Institute projects in 2005.

Friends committee members bring a multitude of skills and experience to make the Friends an important part of the Institute. Committee members have changed throughout the year and we would like to thank past and present members (and their families) for their continued support and commitment.

The models used in Graeme's research are used worldwide but are often poorly characterised from a physiological point of view. "It was important for our collaborative work that a baseline study be conducted to lay the foundation for future research using these models, and this is where my research comes in," Graeme says. "This is needed to understand the processes that contribute to the clinical symptoms of asthma."

While the repeated failure of experiments can be frustrating, Graeme sees the positive side. "These failures can be the most frustrating aspect of research but they also draw me to research, as they force you to challenge your ideas, reassess your approach and solve problems," Graeme says.

As an early career researcher, in a field different to that which he studied at university, Graeme hopes to expand his knowledge base so he can continue his work on understanding lung mechanics and respiratory diseases. In 2005, he'll use his QANTAS Award to travel to the United States to attend an international conference and visit other research laboratories, where he can learn new techniques.

Graeme sees science as a way of gaining knowledge about the natural world in order to solve problems and make informed decisions that can improve and guide the way we live.

"This process not only relies on an excellent understanding of the factors that influence the quality of our research, such as experimental design and informed interpretation of results, but also on a willingness to openly communicate with other researchers by continually questioning and challenging their ideas," Graeme says.

With a background in zoology, it's not surprising to know that when Graeme isn't hard at work in the lab, he can be found bushwalking, birdwatching or partaking in other outdoor activities.

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.



Mike Daube

BA(Hons) HonDSci
Professor, Division of Health Sciences, Curtin University of Technology (to April 2004)



Keith Jones

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



Jenni Ker

President, Friends of the Institute. (from April 2005)



Louis Landau AO

MD FRACP
Professor, School of Paediatrics and Child Health, University of Western Australia.



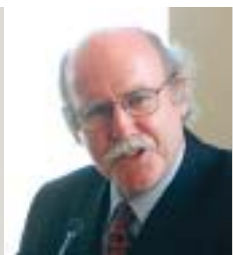
John Langoulant

Chief Executive, Chamber of Commerce and Industry of Western Australia; Member, Senate of University of Western Australia. (from February 2005)



Rebecca Maslen-Stannage

LLB(Hons) BComBCL(Oxon)
Partner, Freehills (to April 2004)



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
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.



Marilyn Stewart

President, Friends of the Institute. (to February 2005)



Robert Ginbey

BA BEd Grad Dip Public Sector Mgt MACE
Company Secretary; General Manager, Administration.

Committees of the Board

The Board of Directors manages the overall business of the Institute and meets six times annually. In order to carry out business effectively, various committees support the Board by offering advice in specific areas.

Appointments and Promotions Committee

Kevin Campbell AM (Chair)
John Finlay-Jones
Bruce McHarrie
Peter Sly
Fiona Stanley AC
Wayne Thomas
Stephen Zubrick

Building Artworks Committee

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

Capital Fund Committee

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

Development Committee

Rebecca Maslen Stannage (Chair to April 2004)
Danielle Blain
Mark Ceglinski
Harvey Coates AO
Richard Court
Steve Davison
Tammy Gibbs
John Langoulant (from February 2005)
Margie Livingston
Bruce McHarrie
Lyn Nixon OAM

Finance Committee

Keith Jones (Chair)
Kevin Campbell AM
Robert Ginbey
John Langoulant (from February 2005)
Bruce McHarrie
Monica Spalding
Fiona Stanley AC

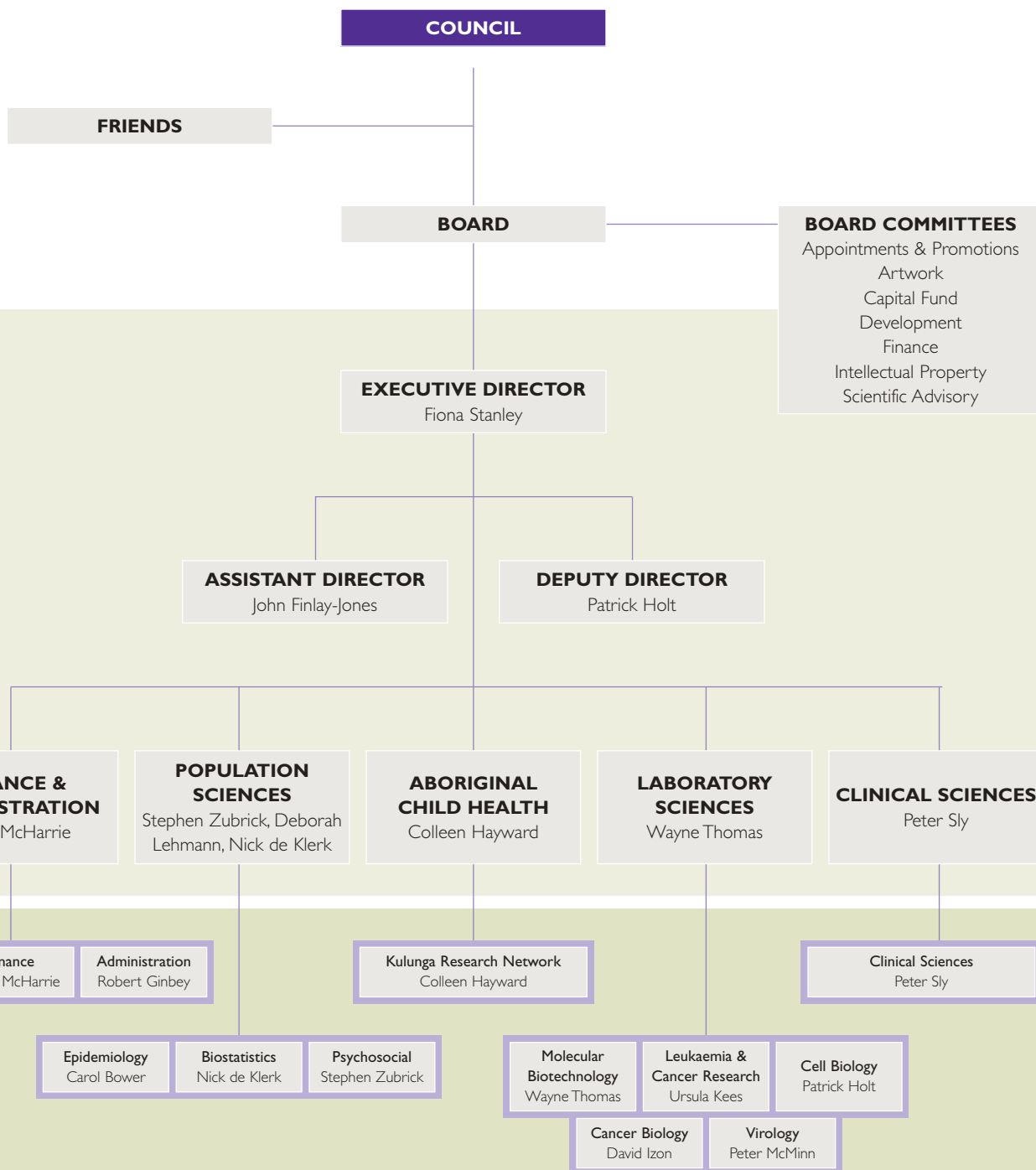
Intellectual Property Commercialisation Committee

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

Scientific Advisory Committee

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

Management/Operating structure



THE EXECUTIVE

DIVISION HEADS

Chief Financial Officer's report



In my previous year's report I made reference to the importance of the State Government's role as a key provider of research support funding. This funding is currently via the Medical and Health Research Infrastructure Fund and, at approximately 25 percent of our total infrastructure funding, it is a significant contributor to our research support needs.

For any funding provider, value for money is a pre-requisite. To assess that aspect, and with the backing of the State Government's Office of Science and Innovation, we commissioned a benefit-cost analysis by the Canberra-based Centre for International Economics. The analysis focussed on two of our major research themes, birth defects and asthma, and sought to quantify the benefits that have accrued to Western Australia.

Some of the notable outcomes of the benefit-cost analysis are:

- the research discovering the link between folate and neural tube defects had a net present value to Western Australia of \$21.6 million, being a benefit-cost ratio of 16.6:1,
- the development of an asthma treatment has an expected net present value of \$116 million, with a benefit-cost ratio of 11.4:1,
- the establishment of this Institute:
 - attracted research funds to WA, amounting to \$9.8 million from national sources and \$2.1 million from international sources in 2003,
 - attracted highly respected researchers to the State,
 - created a critical mass of researchers, leading to greater collaboration efforts,
 - supported higher education, and
 - generated output and employment resulting in a total benefit to the WA economy in 2003 estimated at \$45.52 million.

Our conclusion from this analysis is that the State Government's investment in infrastructure support is indeed generating significant benefits and we strongly encourage the Government to not only continue the funding scheme but to grow it in order to fuel further productivity.

Further evidence of the output of this Institute can be seen in the commercialisation of our research. Commercialisation is one avenue we explore, where appropriate, in our quest to translate our research into action. A number of collaborations exist with pharmaceutical companies and we have now generated two spinout companies, Phylogica Ltd and Advanced Diagnostic Systems Pty Ltd. One notable highlight is, after five years in the making, the recent public listing of Phylogica on the Australian Stock Exchange in March 2005.

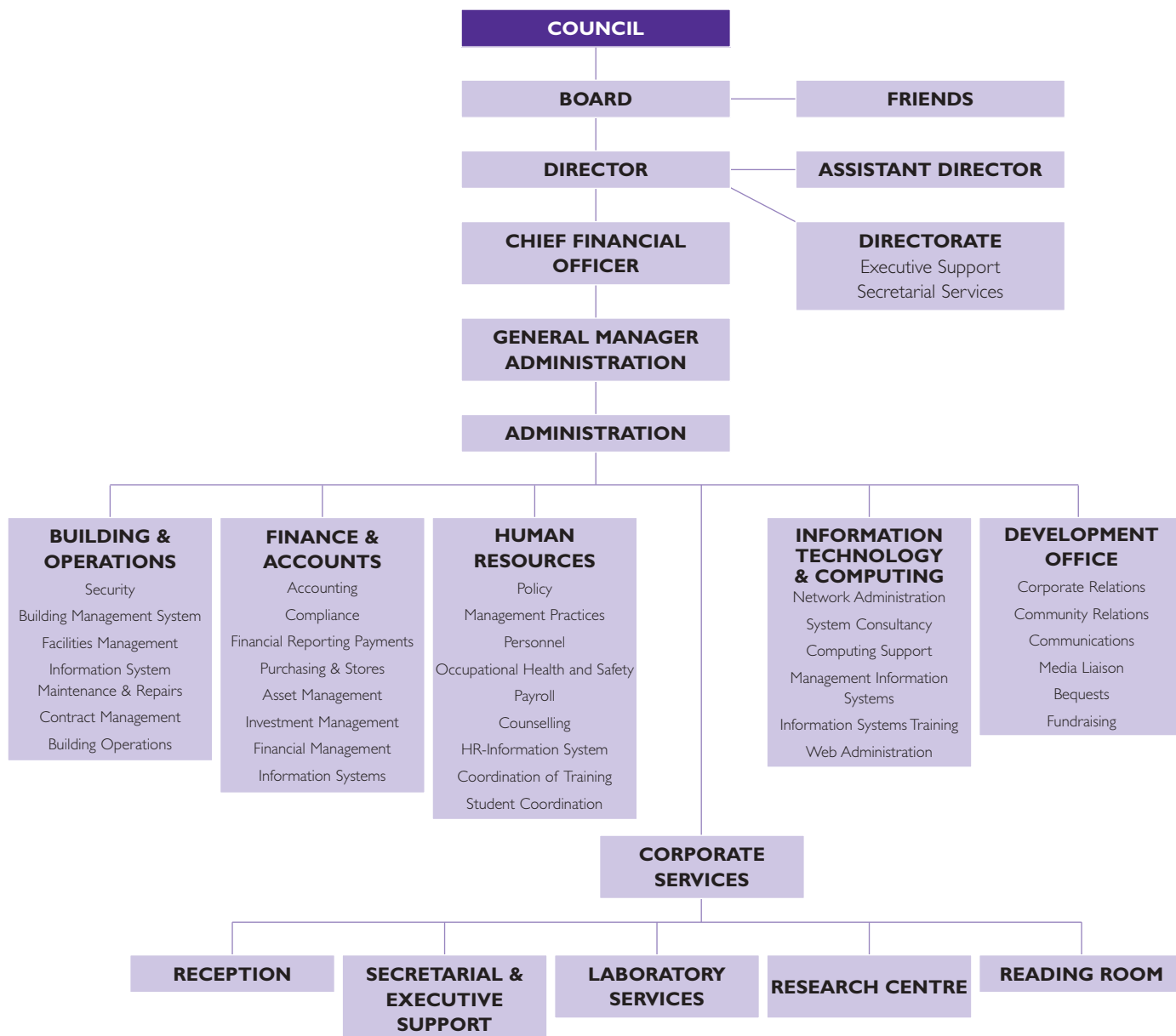
Looking ahead, the Institute has a number of strategic aims and challenges. As is often the case these come with financial implications and therefore one such aim is the establishment of a sound financial footing. The blend and source of research and infrastructure funding is of course fundamental. As can be seen from the financial results in the "Year in Brief" section, our research activities continue to grow, and therefore the burden of support will be an ongoing challenge for the foreseeable future. As described in the next section, the development of our capital fund is critical in securing our financial future and to assist in funding our strategic plans.

Finally, I would like to acknowledge and thank the dedicated team of administrative and research support personnel for their continued, high quality, contribution to research excellence.

Bruce McHarrie
Chief Financial Officer

Organisational chart

Administration and Corporate Services



Researcher Profile

Dr Julie Rowe

Senior Research Officer, Childhood asthma study

Julie Rowe, like many researchers at the Institute, is driven by a desire to do something that makes a difference. She has always been interested in how the immune system responds to bacteria, viruses and vaccines. Today, her research examines how these factors interact with the immature immune system of infants with a hope that it will make a difference to outcomes for children with asthma.

Julie, together with a number of collaborators, has been following a group of around 260 Western Australian children since they were born. She is interested to know how the maturation rate of their immune systems in the early years of life influences susceptibility to infections, the response to vaccinations, and the development of atopy and asthma.

Capital Fund

Our capital fund provides the Institute with the capacity to plan for the future and implement strategic initiatives to enhance the effectiveness of the Institute's 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 \$15 million and we are confident of reaching our target of \$30 million over the next five years. In achieving this aim, Telethon is vital and we are particularly grateful to Channel Seven and the people of Western Australia for their continued support.

Occupational Health and Safety (OHS) Report

The Institute has a commitment to improving health and safety by developing and maintaining appropriate standards of work facilities and methods, providing staff and students with the necessary information to understand the risks associated with their work, and developing health and safety programs at all levels.

Representatives from each of the Institute's divisions attend regular OHS meetings, where issues of interest include incident and accident reports, the management of gene technology research, the use of radioisotopes and quarantinable substances.

In early 2004, our building was assessed for hazards and a range of measures were put in place to address these. Priorities for 2005 will be preparing for new guidelines being implemented by the Australian Quarantine Inspection Service, improving our fire and emergency plans and procedures, and raising the level of awareness of health and safety issues with our expanding population of staff and students who work both on and off-site.



For the past few years, Julie and her team have been working on the cryo-preserved blood samples collected from children in this study. As the children approach their fifth birthdays, Julie is preparing for the next round of blood sample collection. "The support we gain from the children and their families is so critical for our research" Julie says.

Once all of the blood samples are collected, Julie will complete the laboratory work and then start the task of analysing of all five years of data.

Julie says the most difficult thing about her research is dealing with the very precious cryo-preserved blood samples. "If something goes wrong, there is no opportunity to repeat the work, so we try our best to get everything right."

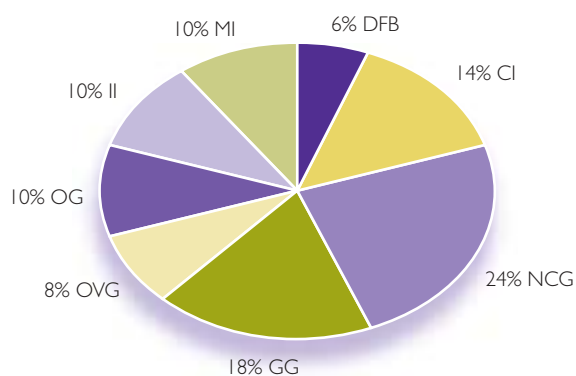
Along with wanting to make a difference, Julie is also driven by the possibility of discovering new things. In the future, she'd like to concentrate her research efforts on examining how the immature immune system responds to the ever-increasing range of new vaccines and the popular new combination vaccines that are being introduced.

But Julie's biggest passion in life is her two children, aged three and one. When she's not working, Julie enjoys spending time with her family particularly taking the kids to parks, the zoo and playgrounds. Julie also loves camping, although hasn't had much opportunity to do it lately, but it's something she looks forward to getting back into.

The year in brief

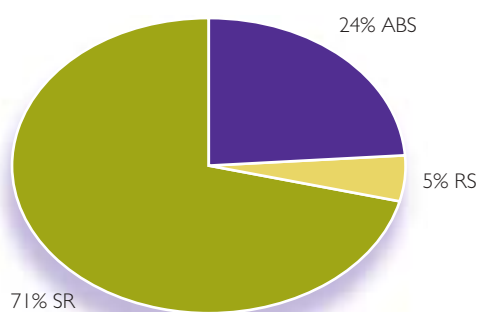
	2004	2003	% Change
Expenditure	21,176,977	20,654,403	2.53%
Total Number of Staff as at 31 Dec (paid and seconded)	320	300	6.6%
Total Number of Honorary and Visiting Scientists during the year	57	59	- 3.4%
Total number of Postgraduate students during the year	56	50	12.0%
TOTAL	433	409	5.9%

Income \$26.39 million



- DONATIONS, FUNDRAISING & BEQUESTS (DFB)
- COMMERCIAL INCOME (CI)
- NATIONAL COMPETITIVE GRANTS (NCG)
- GOVERNMENT GRANTS (GG)
- OVERSEAS GRANTS (OVG)
- OTHER GRANTS (OG)
- INVESTMENT INCOME (II)
- MISCELLANEOUS INCOME (MI)

Expenditure \$21.18 million



- ADMINISTRATIVE & BUILDING SERVICES (ABS)
- RESEARCH SUPPORT (RS)
- SCIENTIFIC RESEARCH (SR)

Research grant income

National Competitive Grants	
National Health and Medical Research Council	6,450,619
	6,450,619
Government Grants	
Department for Community Development	39,709
Department of Education and Training	47,176
Department of Environment	30,000
Department of Family and Community Services	2,013
Department of Health and Ageing	44,684
Department of Health, Government of Western Australia	863,120
Department of The Premier and Cabinet	69,596
Disability Services Commission	34,245
Healthway	419,404
Lotterywest	5,591
Office of Aboriginal and Torres Strait Islander Health	899,453
Office of Aboriginal Health, Family & Social Policy	135,000
South West Area Health Service	64,000
	2,653,991
Commercial Income	
Abbott Australasia	35,163
Advanced Diagnostic Systems Pty Ltd	1,587,626
ALK-AbelløA/S	48,729
Amgen Inc	163,833
Australian Cancer Technology Ltd	55,500
GlaxoSmithKline Australia Pty Ltd	335,615
MedImmune Inc	48,784
Merck Sharpe & Domhe (Australia) Pty Ltd	51,835
Pfizer Pty Ltd	402,663
Rio Tinto Services Ltd	216,471
UCB S.A. Pharma	52,884
Woodside Energy Ltd	60,000
Wyeth Vaccine Research	50,000
Miscellaneous - Overseas	1,863
	3,110,964
Overseas Grants	
International Rett Syndrome Association	57,426
National Institute of Health	1,943,909
World Health Organisation	18,449
Miscellaneous - Overseas	195
	2,019,978
Other Grants	
Alcohol Education & Rehabilitation Foundation Ltd	243,529
Arthritis Australia	23,352
Auseinet (Flinders University)	45,000
The Cancer Council Western Australia	55,000
Children's Leukaemia & Cancer Research Foundation	200,683
Curtin University of Technology	111,725
Cystic Fibrosis Australia	57,926
Flinders University	67,522
Friends of the Institute	11,736
Murdoch University	42,000
RAINE Medical Research Foundation	132,654
Telstra Foundation	76,364
The University of Western Australia	427,712
Western Australia Biomedical Research Institute	1,540
Women & Children's Health Service	167,909
Miscellaneous	10,000
	1,674,651
Total	15,910,205

Our supporters

“Research is expensive, but disease is even more expensive. It costs our community millions of health care dollars every year, it costs families heartache and pain and it still costs too many young lives.” - Professor Fiona Stanley AC

Hope is a precious gift. We would like to thank the following individuals, clubs, corporations, schools and groups for helping us bring hope to the lives of countless children and their families. Your support is, as always, greatly appreciated.

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John Blake
David Howell Hardie
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