TELETHON INSTITUTE FOR
Child Health Research

Annual Report 2002

Contents

Welcome to the Telethon Institute for Child Health Research Annual Report 2002.

The Annual Report is a short form overview only. It gives a concise summary of the activities of the Telethon Institute for Child Health Research (the Institute) for the year ended 31 December 2002.

Detailed research study reports and further information about the Institute is available on our website at http://www.ichr.uwa.edu.au

Telethon Institute for Child Health Research is proudly supported by the people of Western Australia through Channel 7

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

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Hope for children and families

Aboriginal child health page 15
The Institute has established a culturally appropriate program in Aboriginal health research that is integrally linked to the translation of research outcomes into the community.

Death rates in Aboriginal children are still more than three times higher than for non-Indigenous children. The main causes of death for Indigenous infants and children are potentially preventable.

We are:
- Analysing data from the Western Australian Aboriginal Child Health Survey
- Looking at infant care practices in the Aboriginal community
- Looking at ways to reduce otitis media
- Evaluating the health impact of installing swimming pools in remote communities.

Asthma, allergies and respiratory diseases page 17
Asthma is found in one in five people and costs the nation up to $700 million per year in therapeutics and lost productivity.

We are working on:
- Ways to prevent asthma
- Better ways to manage, monitor and treat asthma
- Finding out if bacteria contribute to the development of atopic dermatitis.

Cystic fibrosis is the most common serious inherited condition in Australian children, affecting one in every 2,500 babies.

We are working on:
- Developing better and less invasive tests to measure lung damage in children with cystic fibrosis.

Birth defects page19
Birth defects occur in one in twenty infants born in Western Australia.

We are working on:
- Ways to reduce fetal alcohol syndrome
- Detecting hearing loss in newborn babies
- Setting up an international web-based Rett syndrome database
- Determining the impact of folate on a range of birth defects.

Cancer and leukaemia research page 21
One in 2,000 children will develop leukaemia before their 15th birthday. It is the most common form of cancer in children. Brain tumours account for a quarter of cases of childhood cancer.

Our research focuses on the genetic events that lead to cancer and on developing better and less toxic anti-cancer drugs. We are also using epidemiological studies to look at possible genetic, dietary and environmental causes of cancer.

Developmental disorders page 22
Language impairment is a serious developmental health problem that has long-term consequences for academic, social and behavioural success, and adult employment opportunities.

We are investigating possible genetic and environmental causes of language impairment.

We are also researching:
- Cerebral palsy—our research in this area is recognised world wide
- Newborn encephalopathy—full-term babies who show signs of abnormal brain activity in the first week of life
- Intellectual disability
- Autism.

Infectious diseases page 24
Our work includes:
- Collaborative studies with research institutes in Papua New Guinea, Taiwan and Malaysia
- Increasing public awareness of, and fostering research into, meningitis
- Evaluating new, effective vaccines to reduce the frequency and severity of infectious diseases and overall cost of health care
- Virology research into encephalitis and enterovirus.

Mental health page 26
Recent social and economic trends and changes in family life appear to be making life more difficult for an increasing number of children and adolescents.

Mental health problems, and other problems that emerge in the teenage years, present formidable challenges to families, schools and communities. These problems cause significant distress for the child and their family and often affect socialisation and learning—limiting future life opportunities and health.

Our research is looking at:
- Preventing suicide
- Reducing teenage pregnancy
- Building resilience in teenagers
- Positive parenting programs.

Perinatal epidemiology page 28
This research focuses on the early causes of childhood disease, which often depends on the mother's health as well.

A population database containing information on all children born in Western Australia since 1980, as well as large cohort studies, helps identify these factors. This information also helps to determine the role of pre-term births and growth restriction on a variety of health outcomes.

Recognition of research excellence

The Telethon Institute for Child Health Research exists to improve the health of children, adolescents and their families.

Established in 1990, we are unique in Australia. We adopt a multidisciplinary research approach to major childhood illnesses such as cerebral palsy, childhood cancers, leukaemia, asthma and spina bifida. This multidisciplinary approach is a key strength of our research programs.

Research highlights

- Data from the Western Australian **Aboriginal Child Health** Survey is being analysed. This data on over 5,300 children is a unique snapshot of them and their families, communities, schools and environments. It will provide information on ways to optimise the healthy development of Aboriginal children.

- Rio Tinto and the Institute have teamed up on an innovative initiative with great potential to improve **Aboriginal child health** throughout Australia. Rio Tinto is contributing $2.5 million to the initiative.

- Our **asthma** researchers have investigated many aspects of the complex interaction of genes and environment that leads to asthma and allergy. This has lead to the discovery of:
  - A new concept in the inheritance of the disease
  - Ways to reduce the inflammatory response in the airways and
  - The possible protection against developing allergies by exposure to a messenger molecule called EN-RAGE produced by cats.

Our mission

To improve the health of children through the development and application of research into the causes and prevention of ill health and the maintenance of health.

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

- We have developed a urine test to measure lung damage in children with **cystic fibrosis**. This is a great improvement on previously available tests that have not been sensitive enough and highly invasive for the patient.

- We are setting up an international web-based **Rett syndrome** database to provide important information about the syndrome worldwide. This will serve as a model for data collection in rare disorders.

- In the New England Journal of Medicine we reported on the high level of **birth defects** in babies born to mothers treated for infertility using intracytoplasmic sperm injection (ICSI) and in vitro fertilisation (IVF) compared to naturally conceived infants. This created considerable international interest.

- In a new study, our **cancer** researchers will use epidemiological methods and link genetic, dietary and environmental data to investigate possible causal pathways to childhood cancer.

- Professor Steve Zubrick and Dr Kate Taylor won a prestigious National Institutes of Health (NIH) grant. The $6 million grant is for a five-year study of genetic and environmental factors influencing **speech and language development** in children.

- We commenced work on a major, national **suicide prevention** initiative. Strategies include those aiming to build people's resilience through to protecting people at high risk.

- We were awarded the first National Health and Medical Research Council (NHMRC) public health capacity building grant in collaboration with the School of Population Health, University of Western Australia.

- In collaboration with a consortium, we obtained state government funding (from the Medical and Health Research Infrastructure Fund) to start the Family Connections Database providing family linkage of population data in WA.

- In its first year the **Centre for Developmental Health**, a joint venture between the Institute and Curtin University of Technology, has gone from being a fledgling organisation to winning nearly $9 million in research grants.

Chairman's report

"If the Australian of the Year is intended to embody the ideals to which the nation aspires, then there could hardly have been a more fitting choice than Fiona Stanley.

In a distinguished career, Professor Stanley has combined scientific accomplishment with an outspoken social conscience—a rare and influential mix of qualities."

Editorial *The West Australian* Tuesday 28 January 2003

Professor Fiona Stanley accepts the Australian of the Year award from Prime Minister John Howard. Photo courtesy National Australia Day Council.

Congratulations to our Director Professor Fiona Stanley AC—Australian of the Year for 2003.

This prestigious national award is due recognition for the outstanding achievements and aspirations of an outstanding Australian. The members of the Board, staff, students, and everyone associated with the Institute can feel justifiably proud that we can celebrate this significant event with Fiona.

This was a year of sustained growth for the Institute. The growth in research income continues to maintain the important balance between peer reviewed competitive grants, government contracted research and commercial research contracts. Our research programs were consolidated within the structure recommended by the 2001 international review.

The growth in research activity brings an increase in staff. A total Institute population of over 300—many of whom are part-time—is sustainable in our purpose built facilities.

However, the increase in research activity stretches our means to provide the high level of administrative and corporate services and the new and replacement technology and equipment essential for multidisciplinary, state of the art research.

More than ever we are aware that research can only proceed successfully with sufficient infrastructure. The Board and senior staff continue to address the strategic issues that will sustain this centre of research excellence into the next decade and beyond. The concepts of *optimum population* and *optimum research output* are critical for decision makers who are responsible for providing the infrastructure to support research.

The correct management of risk is strategically important to the Institute. The strength of our human resources systems and policies continues to grow. The regular reports from our Occupational Safety and Health Committee are rigorously scrutinised. At a time of some uncertainty in the insurance industry, the Institute is fortunate that our low number of claims has kept increases to our insurance costs to a minimum, relative to industry benchmarks. This reflects the duty of care of senior management and the diligence of the members of the Occupational Safety and Health Committee.

The Board continues to focus on building strong relationships with commonwealth and state governments, universities, the business community and families. These partnerships increase our support base. And in turn the high quality of our research and the people who undertake it enrich our community.

On behalf of the Board I once again thank the people of Western Australia and Channel 7 for their support of the Institute through Telethon. I also acknowledge our corporate and individual sponsors and donors, and the Friends of the Institute who each year help many young researchers to further their careers.

I thank the members of the Board for their commitment and dedication to Board activities and to the life of the Institute. We face another year of challenge but what a team we have to work with!

I also acknowledge the successful launch of the Australian Research Alliance for Children and Youth and wish them well in their endeavours.

Kevin Campbell AM

Director's report

"By channelling significant funding into a specific area, it has allowed the creation of a centre of international excellence in Western Australia—a place that can hold talent in the state or attract it from other places. This is the kind of strategy that government needs to consider. We need to look at the strengths in our economy, environment and people to find the best places to focus our limited resources. While everyone hates the 'picking winners' approach, that doesn't preclude government from being strategic."

Editorial, "Appointment speaks volumes" in response to Professor Fiona Stanley being named Australian of the Year, Business News, Thursday 30th January 2003.

I am writing this report a day after swimming in the annual race from Cottesloe beach to Rottnest Island with a team of women working the field of paediatrics. The conditions were the worst ever experienced in the history of the event and there were times when we wished we had not entered. But the sheer exhilaration of participating and nearly completing was shared by all of us.

There are parallels between the Institute and the swim—the commitment and competence of the participants, their keenness to work together to achieve a shared aim, the importance of a good boat, friendly, helpful and well trained support staff and lots of good gear and sustenance!

Research is very much a team effort—2002 has seen the Institute go from strength to strength. Examples of the successes of the team overall and individual groups can be found throughout this report.

Improving Aboriginal child health

Our Indigenous research area continues to grow and prosper. Senior Noonygar man Ted Wilkes, former Director of Derbarl Yerrigan, is based at the Institute through a chair with Curtin University of Technology. He brings a wealth of knowledge, experience and contacts into the Kulunga Research Network—a formal partnership between the Institute and the Western Australian Community Controlled Health Organisations.

The Kulunga network provides valuable input and oversight of many aspects of the Western Australian Aboriginal Child Health Survey—a flagship of the Institute. All members of this team, under the leadership of Professors Steve Zubrick and Sven Silburn, are to be congratulated on an outstanding result. Quality data has been collected from all over the state and very high participation rates have been achieved, especially in remote communities.

Ngunytj Tjitji Pirni (the Wongai phrase for healthy mothers and babies) celebrated its 10th birthday in Kalgoorlie this year. Since starting as a National Health and Medical Research Council (NHMRC) grant in 1992, it has grown into a mainstream funded, incorporated organisation run by and for Indigenous women and their families in the Eastern Goldfields. It employs Aboriginal staff and provides antenatal and postnatal care, community support and children's activities to enhance their life chances. The Institute is proud to have been associated with such a program and we congratulate Jenny Carter (coordinator), Dr Christine Jeffries-Stokes, the staff and supporters.

Rio Tinto has teamed up with the Institute on a unique initiative with potentially far reaching benefits for Aboriginal child health throughout Australia. Rio Tinto will contribute $2.5 million to the initiative, contingent on the government matching this dollar for dollar. The Prime Minister endorsed the concept and presented it to the Coalition of Australian Governments in December. The project will span the Northern Territory, Queensland and Western Australia. It is currently in the consultation/development phase.

Translating research into practice

Our excellent population databases are an increasingly precious aspect of our competitive edge. We need to ensure that our core population and other valuable databases, such as the Western Australian Pregnancy Cohort (Raine) study, are adequately funded as part of our infrastructure.

This year saw the 10th anniversary of The Meningitis Centre – established as a partnership with the Institute by concerned parents of children who had died or been affected by bacterial meningitis. It has been an unqualified success in providing parental support and information, encouraging research and, in particular, implementing very effective preventative programs. This is a great example of translating research into action.

The Collaboration for Applied Research and Evaluation (CARE) is our bridge to the state Department of Health. The collaboration sees that research evidence on ways to enhance health are rapidly and effectively communicated to those responsible for policy and programs, and that data to evaluate these are used well. I am extremely pleased with its progress this year.

Professor Fiona Stanley plays in the park with Emily Porter, William Wright, Katie Brennan, Madeleine Naylor-Pratt and Jess Genovesi. Picture by Jody D'Arcy, The Sunday Times.

Research priorities

The NHMRC conducted a national consultation on priorities for Indigenous health research using an interesting process that could become a model for determining research priorities in other areas. This used a *roadmap* produced at workshops held in Perth (at the Institute), Darwin, Brisbane and Melbourne. The final document is excellent and we await its implementation following a unanimous endorsement by Council of NHMRC. Their challenge is that many of the recommendations and research areas are as relevant to the Australian Research Council as to the NHMRC, thus putting the need for cross-disciplinary debate between the two.

A national research priority setting process conducted by the Federal Department of Education, Science and Technology identified four priorities: an environmentally sustainable Australia; promoting and maintaining good health; frontier technologies for building and transforming Australian industries; and safeguarding Australia. Within the health priority are a healthy start to life, healthy ageing and prevention. We are pleased that our research has informed these national priorities and anxiously wait to see how these will influence government and research agency expenditure.

Again I served on the Prime Minister's Science, Engineering and Innovation Council and the Premier's Science Council. Having a seat at these important tables is a mechanism to ensuring that research to improve health is understood and valued.

Other activities

Our new logo and name (changed to Telethon Institute for Child Health Research) was launched during the year. This new look reflects our mission, affirms our identity in the community and provides a positive communication platform for the future.

The 2002 Fiona Stanley Medal was awarded to Geoff Cattach for his dedication to cancer research. He has devoted over 21 years of voluntary work to the Children's Leukaemia and Cancer Research Foundation—helping to raise $3.5 million and establish the Children's Leukaemia and Cancer Research laboratory. We are most grateful to Geoff for his commitment.

We continue to talk with the University of Western Australia's new School of Paediatrics and Child Health about ways to collaborate on research and postgraduate research training. And we enjoy good working relationships with Princess Margaret Hospital for Children and King Edward Memorial Hospital via the new chief executive officer Dr Shane Kelly.

The fundraising committee's accomplishments have contributed to the Institute's financial security. I wish to thank the committee members and particularly Richard Court for his invaluable advice on many approaches.

The Prime Minister launched the Australian Research Alliance for Children and Youth in July. It is now a company and Michael Chaney, chief executive officer of Wesfarmers, its inaugural chair. The state government has generously provided office accommodation. Over the next 12 months the Alliance will progress towards national data networks to monitor health, development and well-being of children and youth; setting a national agenda; implementing an effective communications strategy and setting up a clearing house of evidence of effective interventions to improve outcomes.

The Institute's marvellous research has been the subject of considerable interest from the local media and I commend them on the quality and accuracy of their work. The articles, interviews and reports have highlighted the work that is being conducted to improve children's health and will lift the profile of the Institute.

As with the swim to Rottnest Island there are always rough seas to navigate. The Institute is perceived to be successful and well endowed with new research facilities, exciting and successful research programs and talented, bright and enthusiastic researchers. However we still face considerable challenges. It is crucial that we look to:

- Providing adequate infrastructure funding, including equipment
- Ensuring the future by attracting the brightest and the best researchers and support staff and
- Developing more national and international collaborations to increase the capacity for research excellence and relevance in the state.

This will be the focus of our work over the coming year.

I wish to thank the staff for their hard work, our supportive Board and various committees and all our supporters for another successful year.

Fiona Stanley AC

Senior staff

C Glenn Begley
MBBS PhD FRACP FRCPath
Co-Head of Division Cancer Biology

Adjunct Professor University of Western Australia, Prof Begley previously headed the Human Leukaemia Laboratory and was a senior principal research fellow at Walter and Eliza Hall Institute. His other previous positions include Director of the Bone Marrow Laboratory; Professor Department of Medicine, University of Melbourne; and Director of Western Australian Institute for Medical Research.

Carol Bower
MBBS MSc PhD FAFPHM DLSHTM
Head of Division Epidemiology

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

Nick de Klerk
BSc MSc PhD
Head of Division Biostatistics and Genetic Epidemiology

Adjunct Professor University of Western Australia, Prof 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.

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

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

Pat Holt
PhD FRCPath(UK) DSc FAA
Member of Executive, Deputy Director, Head of Division 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
Co-Head 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 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.

Bruce McHarrie
Bcomm CA
Member of Executive, Chief Financial Officer

Mr 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 Virology

Peter McMinn 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 virologist at Princess Margaret Hospital for Children.

Peter Sly
MD FRACP DSc
Member of Executive, Head of Clinical Sciences

Prof 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, 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 Molecular Biotechnology

Prof Thomas currently holds a Professorship at the University of Western Australia and is a Senior Principal Research Fellow NHMRC. He has been division head since 1990. He has previously worked at the Medical Research Council, Clinical Research Centre London and at Walter and Eliza Institute for Medical Research. He is the chairman of the International Allergen Nomenclature Committee and past chairman of NHMRC grant review panel for inflammation, allergy and haematology.

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

Prof 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.

Researcher Mary Tennant talks with Alison Jones, left,
and Robina Kyanga at the Burringurrah community pool.

Aboriginal child health

Our research shows that death rates in Aboriginal children continue to be more than three times higher than for non-Indigenous children.

The main causes of death for Indigenous infants (SIDS—Sudden Infant Death Syndrome and infection) and children (infection, and accidents and injury) are potentially preventable. While the rate of SIDS has decreased significantly among the non-Indigenous population, it has increased among the Indigenous population.

Aboriginal child health survey

This significant community health survey of Indigenous children and adolescents focuses on health and well-being, educational attainment, adverse health behaviours and psychosocial problems.

Family, child, school and community data on a representative sample of 5,300 Western Australian Aboriginal children aged from birth to 17 years is being analysed. This data will be used to define priority targets for existing services and to develop preventative strategies, health promotion and educational programs to optimise the healthy development of all young Indigenous Western Australians. The first report, on health and social and emotional well-being, will be released in late 2003.

A project has been conducted in the Fitzroy Valley to find out the best strategies to disseminate the results of the survey to the communities. These strategies will be used to disseminate the survey results to other communities and provide a template for use in other research projects.

Bibbulung Gnarneep—Sharing stories

This project is gathering information on the aspirations and hopes of Aboriginal women for themselves and their children, their strengths, and the resources available to them to achieve these aims. This information is being gathered through conversations on a wide range of issues with mothers and others caring for Aboriginal children.

The results will enable policy makers and service providers to develop better programs to assist families to achieve the health and well-being potential for Aboriginal children under their care.

Kulunga Research Network

This is a formal partnership between the Institute and the Western Australian Community Controlled Health Organisations. It was formed in 1999 to build capacity in Aboriginal research. Kulunga is the Nyunga word for children.

Kulunga encourages Aboriginal people to choose research as career, supports Aboriginal people studying in Aboriginal and population health, and educates non-Aboriginal people about research in Aboriginal health.

A business plan for the Network, completed this year, identified three major strategies for Kulunga—research, communication and workforce development.

- Kulunga is involved with research projects within and external to the Institute focusing on Aboriginal children. Staff has also been involved in work groups to develop guidelines on the way to do research with Aboriginal people.
- Communicating with the Aboriginal community about research, particularly its results, is an important function of Kulunga. Kulunga reports on activities through a regular national newsletter and other strategies.
- Kulunga workers have provided lectures to health professionals and students; supported two Aboriginal students doing the Masters in Applied Epidemiology through the Australian National University; and set up a regular weekly series of meetings to discuss research methods for students involved in the Masters of Applied Epidemiology.

Otitis media

Otitis media—or glue ear—is a major health problem in all children, but particularly for Aboriginal children. It is an infection or inflammation of the middle ear that may persist for many months. It can significantly affect a child's hearing and impair speech, language development and learning, and hence employment and social circumstances in adulthood.

Aboriginal and non-Aboriginal newborn babies in the Kalgoorlie-Boulder area have been recruited and are being followed up to age two years to look at demographic, socio-economic, environmental, microbiological and immunological factors that may put some children at high risk of otitis media (OM).

Preliminary results suggest that passive smoking increases the risk of children getting OM, but parents are not aware of this. Breast feeding may protect children from OM, but exclusive breast feeding among Aboriginal women in the area tends to be of short duration. With the local Aboriginal community we are looking at smoking and feeding practices to develop appropriate intervention programs.

Swimming pools project

We have evaluated the impact on the health of children and adolescents of installing swimming pools in remote Aboriginal communities.

During the year, swimming carnivals were held in two communities in collaboration with the Royal Life Saving Society, and our findings were presented to the communities.

Children benefited from the swimming pools. There were improvements in ear and skin health, they attended school more often and for longer periods, crime rates reportedly declined in one community, and residents appreciated the added sporting and social venue for their children.

Detailed research reports may be found on our website at www.ichr.uwa.edu.au

Asthma, allergies and respiratory diseases

Asthma

Asthma is found in up to 20 per cent of people and costs the nation up to $700 million per year in therapeutics and lost productivity. Asthma is the most common chronic illness in children and adolescents and is the most common reason for childhood admission to hospital.

Asthma affects the small airways of the lungs. People with asthma have sensitive airways that narrow when exposed to certain triggers, making it difficult to breathe. The narrowing of the airways is caused by inflammation and swelling of the lining of the airways, the tightening of the muscles around the airways and the production of excess mucus. The result is a reduced airflow in and out of the lungs.

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

Asthma results from a complex interaction between people's genes and their environment. Our work has led to the discovery of a new concept in the inheritance of disease. IL-12 is a gene that stimulates the immune system to resist infections. It can also protect from severe allergy—but only in children who inherit a different type of the gene from each parent. This discovery of a *reverse form of hybrid vigour* is a completely new concept for the inheritance of diseases. It gives new insights into complex diseases, and asthma in particular.

Dr Siobhain Brennan and Kaye Winfield are developing a test to determine lung damage in children with cystic fibrosis. Photo courtesy The West Australian.

Asthma and rhinitis caused by breathing in allergens like pollen and house dust mite is a two stage response. An immediate response releases chemicals that tighten the airways and produce tissue swelling and mucous. A few hours later there is another reaction caused by inflammatory cells from the blood. Our research shows that this later response can be lessened when dentritic cells are activated—these act as a protective patrol for the airways. The dendritic cells take two hours to become active. They exit the tissue by the lymph nodes as the allergic response declines. In future we will look at ways to change this pathway and reduce airway inflammation.

Recent research suggests that developing an allergy to animals, or asthma after being exposed to animals, results from a balance between anti- and pro-allergy influences. Animals produce the allergens that cause disease, but high dose exposure to cats and cows can protect children from developing allergies. It has been thought that this is due to the bacteria found around animals.

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.

Our continuing work on the events in early life that cause allergies has shed some light on the cause of atopic dermatitis. Umbilical cord blood cells taken from babies at birth indicate that the *Staphylococcus* bacteria may be a key contributor to the development of this debilitating disease.

Cystic fibrosis

Cystic fibrosis is the most common serious inherited condition in Australian children, affecting one in every 2,500 babies. In cystic fibrosis the mucus glands cause normal mucus 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. The pancreas is also impaired, preventing the release of enzymes that are needed for the digestion of food.

Children with this condition must have intensive daily chest physiotherapy to break up the build up of mucus in the lungs. Most will also take up to 40 enzyme replacement tablets each day to aid digestion and follow special diets. Regular visits to clinics, hospitalisation and antibiotic treatment are also common. There is no known cure for cystic fibrosis.

The discovery of the cystic fibrosis gene has opened the way for gene therapy and a better understanding of how the mutations to this gene cause disease.

Currently however, lung damage caused by infections is what impacts most on the health of a child with cystic fibrosis. Two major difficulties in combating this disease are that the tests that measure lung damage are not sensitive enough and are highly invasive.

Our research has focused on ways to overcome these problems. We have developed a urine test that measures the destruction of lung tissue. We will continue to study this with the aim of improving the current treatments and testing future therapies.

Detailed research reports may be found on our website at www.ichr.uwa.edu.au

Birth defects

Birth defects occur in one in twenty infants born in Western Australia.

Fetal alcohol syndrome

Fetal alcohol syndrome affects babies whose mothers drink excessive amounts of alcohol during pregnancy. It has life long consequences for the child including intellectual disability, learning difficulties, speech and language delay, and behavioural and emotional problems.

Our research in this area will be used to develop health promotion strategies to reduce the occurrence of fetal alcohol syndrome and its serious and burdensome consequences for the child, family and community. Information from health professionals will be used to identify what information, materials and skills they need to promote safe alcohol consumption among pregnant women.

Hearing loss

It is thought that children who have a hearing loss that is picked up before they are six months of age develop better language skills than those picked up later.

The newborn hearing screening program aims to detect hearing loss in babies in order to start treatment by six months of age. It involves a set of simple screens that are done prior to a baby's discharge from the maternity hospital.

About 30,000 babies have been screened since the program started in 2000. Over 99 per cent of babies passed the screen. About 20 babies were found to have permanent bilateral hearing loss.

The program is being evaluated and recommendations will be made about which is the best model of newborn hearing screening for Western Australia.

Rett syndrome researchers and medical students Seonaid Leonard, Tim Phillips, Sarah Richardson and Luca D'Orsogna gather round Leana Eikelboon. Photo courtesy The West Australian.

Rett syndrome

Rett syndrome is a neurological disorder mainly found in females. It was only recognised as a specific syndrome in 1983. Girls with this condition usually develop normally for the first six to eighteen months of age. Their development then starts to slow and regress. Adult women with Rett syndrome differ in the severity of their disability, but all are incapable of living on their own and need constant care.

The Institute maintains a national register of girls and young women who have this severe neurological disorder. Our database records functional ability, medical problems, and use of medication, health, therapy and education services. The group has been followed for ten years enabling us to monitor how the disorder changes with age.

We are setting up an international web-based Rett syndrome database. This will provide substantial information about Rett syndrome worldwide and serve as a model for data collection in rare disorders.

The results of genetic testing conducted over the past three years allows us to link our information on heath and functional ability to the underlying genetic abnormality. This valuable resource is not available elsewhere in the world and has been provided to study families and doctors to use as a resource.

Spina bifida

Neural tube defects are serious birth defects that involve incomplete development of the brain, spinal cord and/or the protective coverings for these organs. Spina bifida is the most common neural tube defect. It results from the failure of the spine to close properly in the first month of pregnancy. In severe cases, the spinal cord protrudes through the back and may be covered by skin or a thin membrane.

Because of the paralysis resulting from damage to the spinal cord, people born with spina bifida may need surgery and extensive medical care. The condition can also cause bowel and bladder problems, and hydrocephalus—excess fluid in the brain. Most children born with spina bifida live well into adulthood as a result of today's sophisticated medical techniques.

Our researchers, along with international groups, have researched spina bifida and related severe neural tube defects. Increasing the vitamin folate before and during early pregnancy prevents most neural tube defects in babies.

The Institute implemented the world's first program to prevent neural tube defects in collaboration with the Western Australia's Department of Health. Since the use of folic acid supplements has been promoted in Western Australia (from 1992) and food fortification has been allowed (from 1995), the rates of spina bifida and related birth defects in the state have fallen. The rate fell by about 30 per cent in 1996—this has been maintained each year since. This means that almost 100 babies in the state, who in the past would have had spina bifida or a related defect, were born between 1996 and 2002 free of these very disabling conditions.

Deaths resulting from birth defects

We have studied trends in mortality associated with birth defects in Western Australia between 1980 and 1998.

The proportion of stillbirths associated with birth defects increased from 14 per cent in 1980 to 20 per cent in 1998. The number of deaths around the time of birth associated with birth defects decreased from 3.3/1000 births in the period 1980 to 1984 to 2.3/1000 births in the period 1995 to 1998.

This decrease was partly explained by an increase in prenatal diagnosis and subsequent termination of pregnancy and possibly a reduction in neural tube defects due to mothers increasing their intake of folate before and during early pregnancy.

In three quarters of the deaths of children aged less than six years with a birth defect, the birth defect was the major cause of death. Aboriginal children were twice as likely to die from a birth defect compared with Caucasian children.

Next year the infant and childhood mortality profile will be expanded to include the years 1999 to 2001.

Detailed research reports may be found on our website at www.ichr.uwa.edu.au

Cancer and leukaemia research

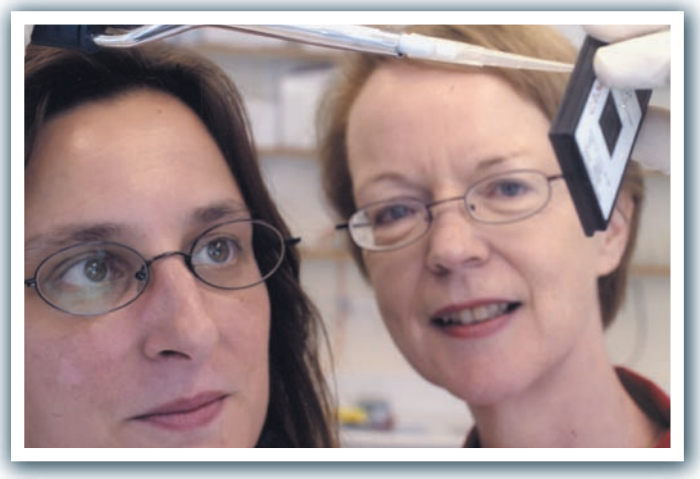
Leukaemia is the most common form of cancer in children, accounting for one third of cases. One in 2,000 children will develop this disease before their 15th birthday. Brain tumours make up a quarter of all cases.

Treatment for children with cancer has greatly improved over recent decades, resulting in a cure for many children. Nevertheless, a quarter of children with leukaemia die and, even in those whose lives are saved, cure is achieved at a significant cost to the child, family and the community.

Our clinical research focuses on the genetic events leading to cancer, and on the development of more specific and less toxic anti-cancer drugs. To do this we must understand the differences between normal and cancer cells—this information is critical for the better diagnosis, classification and treatment of childhood cancer.

One area of our research aims to determine how blood cells are formed and the link to leukaemia development. We have discovered one gene that is critical for both these processes. This gene is needed to make blood cells and has also been associated with 30 per cent of all human T-cell leukaemias. We are researching how a gene responsible for making blood cells can also cause leukaemia.

We have a close relationship with the Oncology Total Care Unit at Princess Margaret Hospital for Children, and are integral members of the largest study group into childhood cancers, the US-based Children's Oncology Group.



Dr Katrin Hoffman and Professor Ursula Kees at work tracking the gene markers they hope will help doctors follow the behaviour of childhood leukaemia. Photo courtesy The West Australian.

A new program of research for the Institute will use epidemiological studies to look at the causes of childhood cancer. Recent research suggests a mother's diet and taking a folate supplement during pregnancy may help to prevent leukaemia in the child.

Researchers at the Institute are heading a multidisciplinary team of experts from around Australia—molecular biologists, geneticists, oncologists and epidemiologists—looking at the genetic, dietary and environmental causes of childhood leukaemia.

Other studies using linked data on Western Australian children with cancer and their families will commence in 2003. These will done through epidemiological studies, and analysing existing data stored at the Western Australian Cancer Registry and in the Maternal and Child Health Research Database.

Detailed research reports may be found on our website at www.ichr.uwa.edu.au

Developmental disorders

Cerebral palsy

Cerebral palsy is the most common physical disability in children and affects one in 500 children born in Australia. Children with cerebral palsy have brain damage that occurred before birth, around birth or in early childhood. It can result in partial paralysis, lack of limb coordination, epilepsy and defects in posture, intellect, vision, hearing and speech. These problems may be mild or severe.

There are many different causes of cerebral palsy. Our research has shown that less than ten per cent of cases are due to problems during labour. Most causes seem to start earlier in the pregnancy. Infections during pregnancy and pre-term births play a more significant role.

The Western Australian Cerebral Palsy Register continues to collect data to monitor cerebral palsy trends overall and in groups such as pre-term or multiple births. We are spearheading a proposal to establish an Australia-wide register. This will enable research that is currently not possible with the small numbers on individual state registers. This proposal was strongly supported by research centres and cerebral palsy service organisations at a national workshop during the year. We are now exploring funding opportunities and discussing options for the structure and location for the national data set.

Parents of children with cerebral palsy produced a brochure to be given to parents when they are first told their child has this condition. It contains information about cerebral palsy and available resources and was launched at the Institute in September.

Data collection for a major case control study of cerebral palsy in full-term and pre-term babies is now almost complete. These data will make it possible to analyse and compare causal pathways to cerebral palsy, survival without cerebral palsy and early death.

Newborn encephalopathy

Newborn encephalopathy (NE) occurs in around one in 300 births. It refers to full-term babies who show signs of abnormal brain activity in the first week of life—they may fit, be very sleepy, stop breathing for periods of time or have problems feeding and swallowing.

In the past this condition has been blamed on the management of the labour. It now appears the problem may start during the pregnancy, or even before it.

Our research examines why some babies have abnormal behaviour in the first few days of life and its long-term consequences. From 1993 to 1996 we enrolled over 800 babies in a study—the largest such study in the world—to collect information on their physical, intellectual and emotional development. By comparing babies with NE to *normal* babies, we have been able to investigate a number of factors associated with NE that were present before, during and after birth.

We have also found children with NE are at a greater risk of disability, and speech and language delay—a critical influence on their ability to learn. This has enabled us to advise those involved in education and intervention services, and parents on the future health and development of their children.

Intellectual disability

Our previous research has defined a group of children born between 1983 and 1992 who have an intellectual disability. This was done using Disability Services Commission education data.

This year we have furthered our study by using the Maternal Child Health Research Database to look at a range of factors—including mother's age, ethnicity, pregnancy and delivery complications, baby's birth weight and condition at birth—that may be linked to intellectual disability in children. Our work will provide significant information on the causes of intellectual disability—information not generally possible to gather elsewhere in the world.

In an exciting development the Intellectual Disability Database will be transferred to the Institute in mid 2003. In preparation for this transfer we have updated the data and developed a new system for ascertaining intellectual disability in Western Australia. The new system will be a considerable addition to the network of population based childhood databases coordinated from the Institute.

Autism

Autism affects approximately one in 500 children. Children with autism have stereotypic or repetitive behaviour and difficulties with communication and socialisation. It is usually diagnosed at around 3 to 4 years of age.

Our research looks at factors that may be linked to autism including problems during pregnancy or delivery, congenital defects, and childhood illness and disability. The Institute manages the Western Australian Register for Autism Spectrum Disorders recording information on all children diagnosed with autism since 1999. The Register is invaluable for describing the patterns of people who are diagnosed each year.

Speech and language development

Language impairment is a serious developmental health problem that has long-term consequences for academic, social and behavioural success, and adult employment opportunities.

Specific Language Impairment (SLI) affects approximately seven per cent of children with otherwise normal development—normal hearing, normal intellectual abilities and normal physical development. But these children have difficulty with language—they are late in starting to talk and continue to lag behind their peers into adulthood.

We do not know what causes SLI but recent twin and family studies suggest it may be strongly genetically determined.

Associate Professor Kate Taylor has fun with four-year-olds Karen and Megan Adams. Twins with normal language development as well as those with language difficulties are being studied. Photo courtesy The West Australian.

The Looking at Language study will help us understand more about possible factors that influence language abilities in the preschool and school years. This study will collect valuable evidence from a population sample of Western Australian twins and single-born children aged between two and eight years, and their family members.

We are investigating possible genetic and environmental causes of language impairment using new and precise measures (markers) of young children's grammatical development and measures of environmental risk.

Detailed research reports may be found on our website at www.ichr.uwa.edu.au

Infectious diseases

International collaborations

The Institute is a member of the Buttressing Coalition of the Papua New Guinea (PNG) Institute of Medical Research. We have been looking at the impact of pneumococcal and routine infant immunisations on mortality in Tari, Southern Highlands Province, PNG.

We have also been investigating whether immunising pregnant women with pneumococcal polysaccharide vaccine might reduce the high rates of death and disease in infants from pneumococcal infections. Our findings, as well as those in several other developing countries, justify large scale maternal immunisation trials.

Meningitis

Meningitis is one of the few diseases that can kill within hours. The Meningitis Centre aims to provide information to families affected by meningitis, and to increase public awareness and foster research into the disease.

Vaccine trials

The development and use of new, effective vaccines and treatment results in reduced frequency and severity of disease and reduces the overall cost of health care.

The Vaccine Trials Group is a collaborative project between the Institute, the University of Western Australia School of Paediatrics and Child Health and Princess Margaret Hospital for Children. It provides a coordinated approach to the development, delivery, assessment and promotion of vaccines and allergy treatments in our community.

Our recent studies include work with combination vaccines such as Measles-Mumps-Rubella-Varicella (Chicken pox) and Diphtheria-Tetanus-Pertussis (whooping cough)-Polio-Hepatitis B.

The Vaccine Impact Surveillance Network

The Network assesses the impact of vaccines on the burden of infectious diseases.

We have been collecting information on meningitis and pneumonia caused by the pneumococcus bacterium (or *Streptococcus pneumoniae*). There are many different types of pneumococcus. The long term effects of this infection can be devastating and include cerebral palsy, hearing loss, epilepsy and learning difficulties.

A new vaccine (Prevenar™) has recently been licensed in Australia but is only offered free to children at high risk. Our database will help evaluate the impact of this new vaccine and provide information to policy makers and the general public. Ongoing surveillance will monitor the types of pneumococci circulating in the community.

Shontae Smith and paediatrician Peter Richmond are hoping the vaccine study of preschoolers will lead to fewer vaccinations for children in the future. Photo courtesy The West Australian.

Virology research

Murray Valley encephalitis and Japanese encephalitis are potentially fatal mosquito-borne diseases of the Asia-Pacific region.

Our work in this field consists of:

- Molecular genetic studies of Murray Valley encephalitis (MVEV) virulence determinants using an infectious cDNA clone of MVEV developed in our laboratory
- Looking at virus–host interactions that lead to the development of encephalitis and host determinants of susceptibility to infection using the mouse model
- Developing a vaccine.

Enterovirus is a gastrointestinal virus that can cause paralysis in toddlers.

Our research, being done in collaboration with research groups in Taiwan and Malaysia, started in response to the large epidemics of neurological disease due to enterovirus 71 (EV71) in Australia and Southeast Asia since 1997. We are studying the molecular epidemiology and genetics of virulence of EV71 in the region with the ultimate aim of developing a genetically defined, live-attenuated vaccine.

Detailed research reports may be found on our website at www.ichr.uwa.edu.au

Mental health

Recent social and economic trends and changes in family life appear to be making life more difficult for an increasing number of children and adolescents.

Mental health problems such as attention deficit hyperactivity disorder (ADHD), early childhood behaviour difficulties, and other problems which emerge in the teenage years—such as eating disorders, depression, substance misuse and crime—present formidable challenges to families, schools and communities.

Apart from causing significant distress for the child and their family, many of these problems also affect socialisation and learning and therefore limit future life opportunities and health.

The Institute, through its longitudinal studies and state population surveys, has identified some of the major causes of child and adolescent mental ill health. These studies show the early years of a child's life and the formative years of schooling are crucial in setting developmental pathways into adult life. We are using this information to develop effective early interventions to improve the quality of life for vulnerable children, and help all children achieve their potential.

Our population data on the causes of childhood vulnerability is also informing government and public policy to better support families, schools and communities in their shared responsibility for the health, social well-being and competence of the next generation of Australians.

Suicide prevention

Suicide is a tragic event. It has a profound personal effect on all associated with the person who dies—family, friends, and members of the local community.

The grief and distress associated with suicide is immeasurable. Affected families and friends typically experience great difficulties coming to terms with these deaths, which are often unexpected and difficult to ever fully understand.

The CommunityLIFE program is a nationwide initiative led by the Institute and Curtin University of Technology's Centre for Developmental Health. This program seeks to build community capacity for suicide prevention and is based on the LIFE (Life Is For Everyone) framework, a comprehensive framework for suicide prevention activities in Australia.

It supports the implementation of a wide range of strategies across entire communities. It includes strategies to build people's resilience (life promotion) through to protecting people at risk (life protection).

Teenage pregnancy

Many young girls have unrealistic expectations of having a baby and caring for a young child. Unplanned pregnancy is common among adolescents.

We are evaluating a program that aims to reduce pregnancy among year 10 girls in schools in the northern suburbs of Perth. Girls care for a very realistic simulated 'baby' and participate in a one week hands on health education program.

This program shares information on the steps that young women can take to ensure their own health before and during pregnancy to promote healthy birth, maternal and child health outcomes.

Building resilience in teenagers

We are evaluating the state-wide roll out of a program aiming to prevent depression by teaching positive thinking, problem solving, negotiation, relaxation and assertiveness to children as they enter puberty.

Positive Parenting for Preschoolers

Our earlier research has shown that children who are reared with a predominantly positive style of parenting are less likely to have a range of mental health problems than those reared with more coercive and negative styles of parenting.

We are evaluating the Western Australian implementation of Triple P (Positive Parenting for Preschoolers Program) through community and child health services.

Detailed research reports may be found on our website at www.ichr.uwa.edu.au

Perinatal epidemiology

The overall focus of this research is identifying the early determinants of childhood disease, which often depends on the mother's health as well.

A population database containing information on all children born in Western Australia since 1980, as well as information from large cohort studies, helps identify these early determinants as well as the role of pre-term birth and intrauterine growth restriction on a variety of health outcomes.

RASCALS Study

The RASCALS Study has collected data from nearly 5,000 mothers who had a baby in the years 1995 to 1997 in Western Australia. Mothers were asked about their experiences before, during and after pregnancy including questions on breast feeding, baby's sleeping positions, rubella immunisation, alcohol consumption, smoking, folic acid intake and so on.

A smaller group of the mothers have been sent a questionnaire each year during the week of their child's birthday to assesses among other things, the child's development at home and school and the general health of their family. This information will be used to improve the health and well-being of families within Western Australia.

Western Australian Pregnancy Cohort (Raine) Study

For the past 15 years we have tracked the lives of 2,860 children. Our original aim was to find out the benefits of ultrasound scans in pregnancy. We found that in a normal pregnancy multiple ultrasounds were of no benefit—this led to worldwide recommendations that scans be carried out once at about 18 weeks gestation.

Asthmatic Jasmine Beynon prepares to have a breathing test watched by her identical twin Amber, who is not asthmatic, and clinical coordinator Kerryn Coleman. Photo courtesy The West Australian.

Since then the study has expanded. Assessments of the children have been carried out at ages one, two, three, five and a half, eight and ten years. Next year we will collect information on adolescents focusing on exercise, diet, asthma, allergy and the environmental and life factors that may impact on their future health.

This year, using the five year follow up data and DNA from the blood tests, researchers found a gene that partly explains why some children develop mild, and others develop severe, asthma.

Western Australian Twin Child Health Study (WATCH)

This major study arose out of the Maternal and Child Health Research Database and uses data on all multiple births between 1980 and 1998. It is the only population based twin study in Australia.

When it started in 1997 the study sought to investigate the roles of genes and the environment in the development of asthma and allergies. Since then it has formed the basis of other studies looking into early language development and child temperament. It is a powerful resource in seeking to untangle the roles of genes and the environment in health and disease.

Detailed research reports may be found on our website at www.ichr.uwa.edu.au

Collaborations and joint ventures

BioMed Alliance WA

The BioMed Alliance was formed in 2001 to foster collaboration between medical research organisations in Western Australia. The Lions Eye Institute, Telethon Institute for Child Health Research, Western Australian Institute for Medical Research and the Western Australian Biomedical Research Institute were founding members.

The Alliance seeks to become the peak industry body for medical research in the state—to create a focal point where opinions and information affecting our industry can be sought; and to provide a stronger voice to government and industry on medical research issues.

Executive officer Simon Holtby has been appointed to assist in the formalisation of the Alliance's aims and to encourage a wider membership base so the Alliance truly represents the state's medical research industry. The beginning of 2003 saw the addition of the Lions Ear and Hearing Institute and the Asthma and Allergy Research Institute.

The Alliance was an exhibitor at the BIO 2002 conference in Toronto. This annual conference is one of the biggest of its kind for the biotechnology industry. It is a significant occasion to promote the state's research and identify potential partnering opportunities.

Centre for Developmental Health

The Centre for Developmental Health is a joint venture between the Institute and Curtin University of Technology. The first of its kind in Australia, it is an innovative research centre dedicated to improving children's lives. Its establishment cements developmental health as a critical area of applied academic research.

The Centre brings together researchers from different disciplines to integrate new knowledge on what influences infant, child and adolescent development and how families, schools, communities and society can support this development.

In its first year the Centre has gone from being a fledging organisation to winning nearly $9 million in research grants. Major projects are looking at:

- Language acquisition in children
- Suicide prevention
- Positive parenting for preschoolers
- Aboriginal child health.

Further information about the Centre and its research is available on the internet at http://cdh.curtin.edu.au

Stepping up to the health study challenge with a $3 million grant are researchers D'Arcy Holman, Rebecca Coghlan, James Semmens, Delia Hendrie, Liz Milne, Matthew Knuiman, Fiona Stanley, Garth Kendall, Max Bulsara, Eugen Mattes, David Lawrence and Marjorie Caw. Photo courtesy The West Australian.

Collaboration for Applied Research and Evaluation (CARE)

The Collaboration for Applied Research and Evaluation works to ensure that the Institute's findings on ways to enhance the health and well-being of children is rapidly communicated to those responsible for delivering health and social programs in our community.

Established in 2001, it streamlines the links between the Institute's researchers and government and non-government agencies.

The Collaboration has developed a series of linked key themes to its work. Within these themes, a series of state government funded projects are underway. Projects are negotiated to ensure there is a good fit between the research agenda of the Institute and government priorities.

Current primary work themes are:

- Assisting to identify ways of translating early years research evidence into practice
- Providing access to the Institute's maternal, child and youth health information systems
- Providing research and evaluation services for community and child health programs
- Providing research and policy advice on maternal, child and youth health issues within Aboriginal communities.

The Collaboration also provides start-up support for research projects within the Institute to enable research staff to focus on research activity.

Affiliated groups' reports

Amanda Young Foundation

The Amanda Young Foundation had a very productive year, hosting a number of successful fundraising events. The inaugural Champion's Breakfast saw a panel of leading sportsmen and women sharing their sporting stories with a curious audience. The third annual Young Leaders' Eco-Health Summit was held and Amanda's Garden was open to the public once again. The 2002 Rowing Fun Regatta was the best yet, attracting a record 80 crews. These events are attracting a growing number of participants each year.

The Foundation again participated in the annual meningococcal awareness campaign in conjunction with The Meningitis Centre and the Department of Health.

The Management Committee are:
Barry MacKinnon AC (Chair), Desarae Biddle (Coordinator from February 2003), Peter Dingle, Bruce Langoulant, Val Mayger, Graham Rixon, Belinda Turner (Coordinator to February 2003), Victoria Woollard (from May), Barry Young, Lorraine Young, Wendy Zuideveld.

The Amanda Young Foundation's 2002 Eco-Health Young Leaders Summit.

Friends of the Institute

The Friends are a valuable addition to the Institute community. They are a volunteer group that raise awareness of the Institute and advocate for child health research. They also support our work by making significant contributions to research projects.

The Friends:
- Funded conference registration and airfares for three Institute researchers
- Supplemented an Aboriginal student scholarship
- Funded travel and accommodation to enable the Newborn Behaviour Study to complete assessments in regional Western Australia
- Purchased a television, video and kids sofa for the Western Australian Twin Child Health Study (WATCH) waiting room.

The Margaret River Friends are supporting a marijuana education pilot program to be implemented in Margaret River high school by researchers from the Institute and Curtin University of Technology. The local community is enthusiastically supporting the project, which will educate young people about marijuana in an effort to reduce its use.

In 2002 the Friends held a special screening of the movie Charlotte Gray and the annual ladies golf day, which was a huge success again. The Margaret River Friends held their first golf day as well as a number of smaller fundraisers. The Friends also produced a promotional brochure.

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 current members for their continued support and commitment.

Committee members throughout the year include:
Perth—Marilyn Stewart (President), Vicki Haunold (Vice-President), Jenny Elphick (Treasurer), Tammy Gibbs (Secretary), Sue Bolto, Lyn Buchan, Helen Chipper, Lois Egerton Warburton, Noela George, Robert Ginbey, Jackie Goldfinch, Julanne Griffiths, Lesley Maff, Ursula Prince.
Margaret River—Deb Jacob (President), Helen Noakes (Vice President), Jennie Buckingham (Treasurer), Jan Matthews (Secretary), Christine Wilder (Secretary), Jamie Ashton, Jim Boyd, Aileen Budge, Sandy Collins, Sue Evans, Pat Gray, Lynley Madson, Madeleine Miles, Jenn Morrell, Jan Smith, Colleen Wild (to May), Rae Willis.

Louisa Alessandri Memorial Fund

Over the past four years the fund has perpetuated the work of a notable and much loved Institute epidemiologist.

In 2002 the Dr Louisa Alessandri Scholarship was launched. This will be awarded to a student with a disability in the 2003 academic year. This year's public oration on *In those we trust: investing in social capital* was given by Dr Neale Fong. Sales of the cookbook *Good Food, Good Company,* written by Louisa's mother Phyllis Alessandri, continues to assist the fund's activities.

The Dr Louisa Alessandri Award in Excellence in Research is given to a person who has contributed in an important way to the Institute. Jette Ford was this year's recipient. She has a long association with the Institute in cancer research.

Meningitis Centre

The Meningitis Centre aims to provide information and support services to families affected by meningitis, to increase public awareness and foster research into meningitis. This year the Centre celebrated its 10th anniversary.

The inaugural National Meningitis Awareness Week was an outstanding success. This was followed by the state's annual meningococcal awareness campaign, held from July to September in conjunction with the Department of Health and the Amanda Young Foundation.

The federal government announced the new meningococcal C vaccine would be available free as part of the routine childhood vaccination schedule from early 2003. Next year The Meningitis Centre will focus attention on pneumococcal disease and lobby the Federal Government to make the pneumococcal vaccine part of the routine childhood vaccination schedule.

The Management Committee are:
Bruce Langoulant (Chair), Desarae Biddle (Coordinator from February 2003), Julie Dockerty (from December), Treacy Elliott (Project Officer—from November), Robert Ginbey, Sarah Johnston, Michael Kailis, Tony Keil, Deborah Lehmann, Barry MacKinnon, Barry Thornton (Chief Executive Officer—from June), Belinda Turner (Coordinator to February 2003), Tony Watson.

Students and awards

Students

A number of innovative postgraduate research and honours projects are being undertaken at the Institute by some of the best students in Western Australia. Students are currently studying asthma, cancers, mental health and birth disorders.

The Institute provides a multidisciplinary research training environment in a purpose built facility. Students work primarily at the Institute but can also access all of the supports available from their tertiary institution.

Daisy and Harcourt Harper Memorial Fund

The fund was created in 1996 in memory of Daisy and Harcourt Harper.

It was with sadness that we heard of the death of Cecilie Harper in September. Cecilie and her sisters Nan and Sue Harper provided the means for the memorial fund to be established.

The Daisy and Harcourt Harper Memorial Fund assists and encourages the professional development of staff, students and community members allied with the Institute who are working on projects associated with:

- Better parenting
- Improved infant and childcare practices by parents and carers
- Promoting good health for Aboriginal children
- Providing research training and professional development for Aboriginal staff

This year the fund subsidised the fees for Daniel McAullay, research coordinator for the Kulunga Research Network, to undertake the Postgraduate Certificate in Health Economics. It will also assist Annette Stokes to attend the 7th National Rural Health Conference in Hobart next March. Annette, a member of the Eastern Goldfields Wongatha community, is a research assistant in Kalgoorlie and plays a vital role in several otitis media studies.

Young Investigator's Award

This award recognises scientific excellence in research among doctoral or postdoctoral students at the Institute. The winner has the opportunity to present their work at international forums in Europe and/or North America. Professor Pat Holt funds this award.

This year's winner was Dr Julie Rowe in recognition of her work studying the development of vaccine responses in children. She will present her work at forums across the United Kingdom including the 3rd International Meeting of the Edward Jenner Institute for Vaccine Research.


CHILD
HEALTH
RESEARCH

Board of Directors

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Chair,
Telethon Institute for
Child Health Research

Harvey Coates
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

Mike Daube
BA(Hons) HonDSci

Director General, Department of Health

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BBus ACA CPA

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

Louis Landau AO
MD FRACP

Professor, Dean, Faculty of Medicine and Dentistry, University of Western Australia

Rebecca Maslen-Stannage
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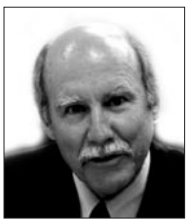
Partner, Freehills



Graham Mitchell AO
RDA BvSc FA CVSc PhD FTSE, FAA

Principal, Foursight Associates Pty Ltd

Fiona Stanley AC
FASSA MD MSC FFPHM FAFPHM MFCCH FRACP (Hon) FRACOG

Director, Telethon Institute for Child Health Research; Professor of Paediatrics, the University of Western Australia; Member, Prime Minister's Science, Engineering and Innovation Council

Marilyn Stewart

President, Friends of the Institute

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 that offer advice in specific areas support the Board.

Appointments and Promotions Committee

Kevin Campbell AM (Chair)
Bruce McHarrie
Peter Sly
Fiona Stanley
Wayne Thomas
Stephen Zubrick

Building Artworks Committee

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

Capital Fund Committee

Kevin Campbell AM (Chair)
Harvey Coates
David Berinson
Bryce Denison
Robert Ginbey
Rudi Gracias (from January 2003)
Bruce McHarrie
William Rayner (to December)
Fiona Stanley AC
Fred Stone

Finance Committee

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

Fundraising Committee

Rebecca Maslen-Stannage (Chair)
Danielle Blain
Harvey Coates
Richard Court
Paul Davis
Tammy Gibbs
Bruce McHarrie
Maurice Swanson (until August)

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
Robert Ginbey
Peter LeSouef
Richard Loh
Bruce McHarrie
Susan Prescott
Richard Prince
Fiona Stanley AC
Geoff Stewart
Wayne Thomas
Charles Watson

Chief Financial Officer's report

Last year I reported on the then recently completed International Scientific Review. The review panel made many valuable recommendations and in 2002 the senior management and Board prioritised those recommendations. They now form part of our roadmap for the future.

In addition to making recommendations about specific areas of research, the report commented on our capacity to maintain, or develop as the case may be, a leading edge in child health research. This capacity depends on such issues as staff development and retention, succession planning, attracting new researchers, developing bioinformatic capabilities, providing research equipment, database management, general information management and so on.

A common denominator to many of the initiatives is funding. Income from research and infrastructure does not cater for strategic activities of this kind. In addition, a reliable and sustainable source of income is required in order to be able to plan with confidence. Building our capital fund—in effect our strategic fund—is therefore vital to our future. Income from this fund already provides for many research related initiatives that would otherwise not be possible.

We aim grow our capital fund to $30 million—an aim endorsed by the International Scientific Review panel. Consequently our Development Office capacity has been enhanced and a very effective fundraising committee of the Board established. Telethon continues to be a key contributor to the Institute and we are grateful to Channel 7 and the people of Western Australia for their support.

Our research and strategic activities are underpinned by a robust support mechanism. Besides the building, its facilities and equipment, research infrastructure ranges from the washing of laboratory glassware through to the directorate—with all the usual administrative activities in between.

Income to cover these functions comes from a variety of sources. However, cumulatively it remains inadequate to cater for the complex needs of an independent medical research institute. State government funding is a vital component, yet when compared with other states Western Australia falls well short. This impacts significantly on Western Australia's presence in the national and international arena and limits our contribution to an innovative Australia. Along with other medical research organisations we will continue to work with the state government on this matter.

One of our strategic aims is to develop commercial opportunities. Our previous activities have primarily involved collaborative research agreements with pharmaceutical companies. These have generated important networks within that industry and we will continue to identify similar opportunities. In addition, we will be seeking opportunities where the Institute has the

potential to gain further from the commercial development of the science.

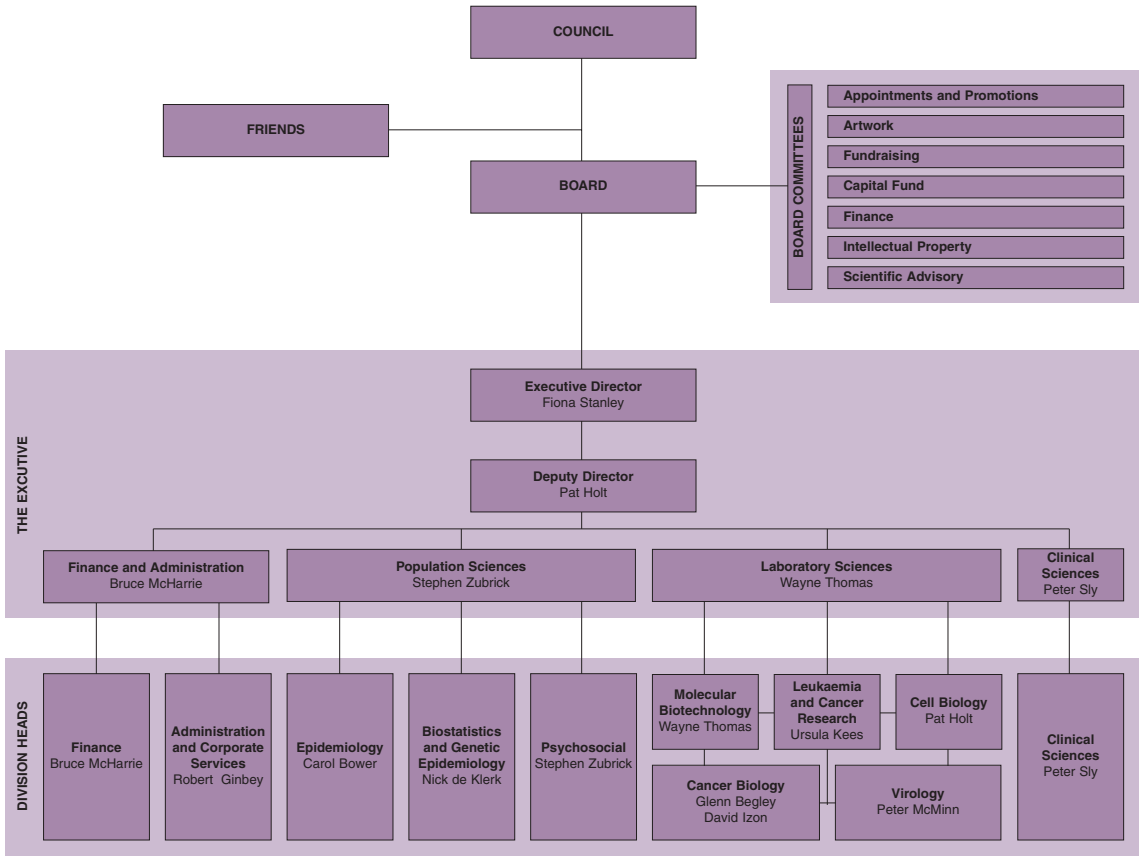
For example, we are endeavouring to launch our first spin-off company in the field of drug discovery. The technology is the result of many years of research funded by NHMRC in Australia and the National Institutes of Health in the US. We are seeking funds in a difficult investment climate, however if successful we will be able to develop this technology further and leverage benefits from the earlier research funding. Of course we need to balance our commercial activities with the overall aims of the Institute—providing information and findings from our research for the public good.

When these and the many other initiatives are taken as a whole, 2003 and beyond are set to be dynamic years. Commencing the new year with our Director being awarded Australian of the Year is symbolic of that.

Finally, I acknowledge the efforts of the administrative team whose performance is dependable, consistent and of a high standard.

Bruce McHarrie

Management/Operating Structure



Administration and corporate services

The increased growth of research income during 2002 was our greatest challenge. The growth was clearly an indication of the success of our researchers in being able to compete so successfully for international, national and state research grants. The challenge has been to match this excellence in research with excellence in cost effective research support and administrative services.

Some of the indicators of growth during the past 12 months include:

- Numbers of staff and students serviced by the Institute increasing from less than 280 to more than 320
- The number of grants increasing from less than 200 to more than 300
- Research income increasing from $10 million to over $12 million
- Purchase orders increasing from less than 2,000 to more than 2,500
- Staff/student inductions increasing from less than 50 to more than 100
- Number of computers serviced increasing from 200 to 260
- The number of emails increasing from 360,000 to more than 500,000.

It is a credit to Chief Financial Officer Bruce McHarrie, the section managers and their staff that they have addressed these challenges with confidence and enthusiasm at a time when everyone is conscious of the need for budget restraint.

Particular initiatives during 2002 included:

- Expanding the salary packaging benefits to the 280 staff on the Institute payroll
- Consolidating the administrative management information system
- Upgrading the Institute asset register
- Providing services for groups linked to the Institute including the Australian Research Alliance for Children and Youth and the Children's Clinical Research Facility
- Consolidating the Building Emergency Response Team (BERT)
- Building modifications
- Reviewing information management across the Institute and in particular for the Division of Population Sciences
- Participating on the working party assessing the feasibility of a School of Paediatrics and Child Health in conjunction with the former University of Western Australia Department of Paediatrics
- Participating in the Institute planning day
- Bolstering executive support to the Population Sciences Division, which now comprises over 50 per cent of the Institute's staff and income
- Recruiting a community liaison officer, Dale Anderson
- Recruiting the new manager of fundraising and corporate relations, Paul Davis.

I acknowledge the important executive leadership provided by our Chief Financial Officer Bruce McHarrie to whom the administration reports and is accountable.

I would also like to recognise the important leadership role of the administration managers and the administration managers' forum. This complements the framework of internal committees all of whom report to the executive—the House Committee, Human Resources Reference Group, IT Steering Committee, Occupational Safety and Health Committee and sub committees, and the Research Centre Management Committee.

Occupational health and safety

The Occupational Health and Safety (OHS) Committee provides a forum for resolving safety issues that may arise at the Institute. Representatives from each division meet regularly to discuss internal safety and health practices, to make recommendations to management for safety policy, to resolve problems, monitor accidents and incidents, discuss OHS training requirements and plan for emergencies.

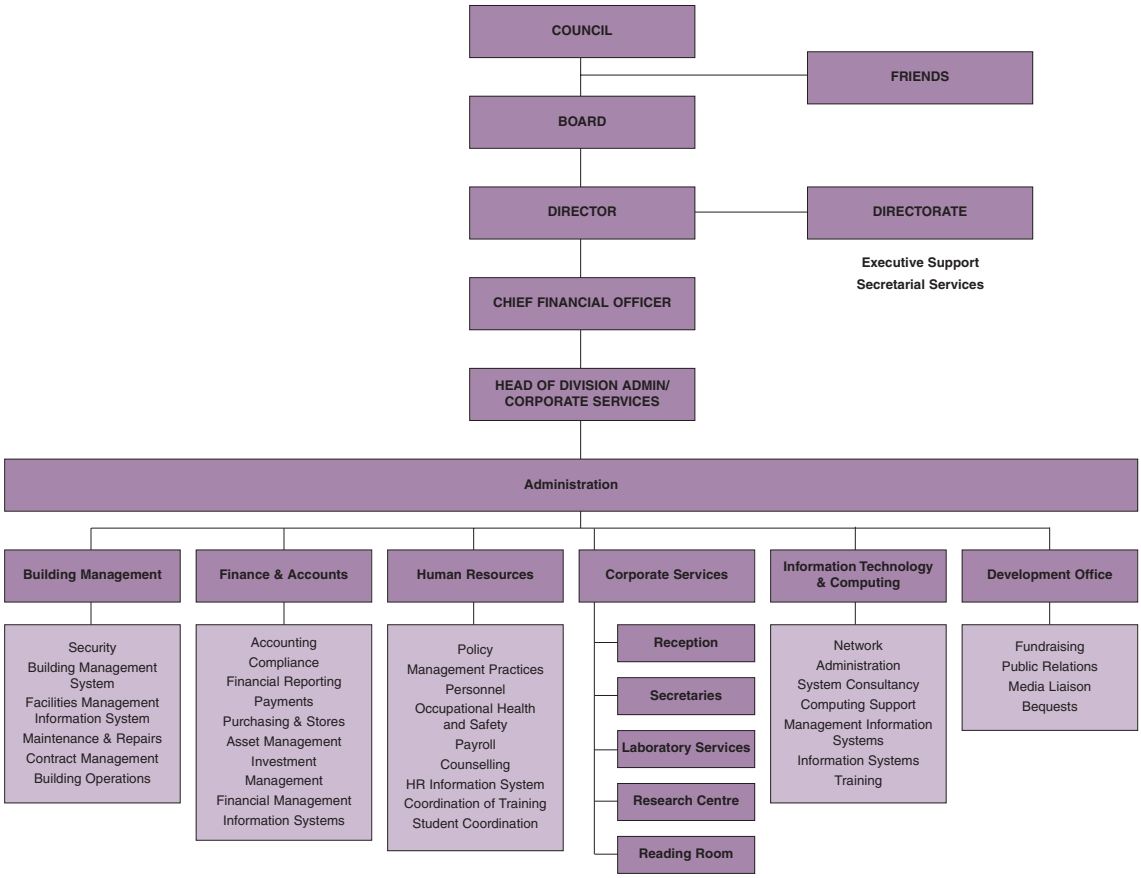
These representatives report back to their respective divisional meetings to ensure members of staff are aware of decisions made or new procedures. Staff can discuss safety matters with their representatives in confidence or as a preface to the concern being formally raised at a meeting. The committee aims to resolve any issues put before it as promptly as possible.

The coordinator promotes awareness of health and safety issues within the Institute by providing regular reports and newsletter articles. Training staff in areas such as manual handling, ergonomics, first aid and fire safety continues to be a priority.

Robert Ginbey

Organisational Chart

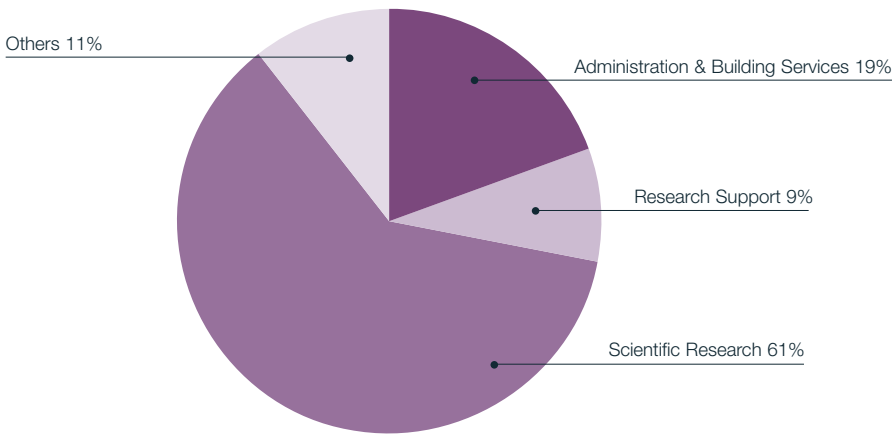
Administration and Corporate Services



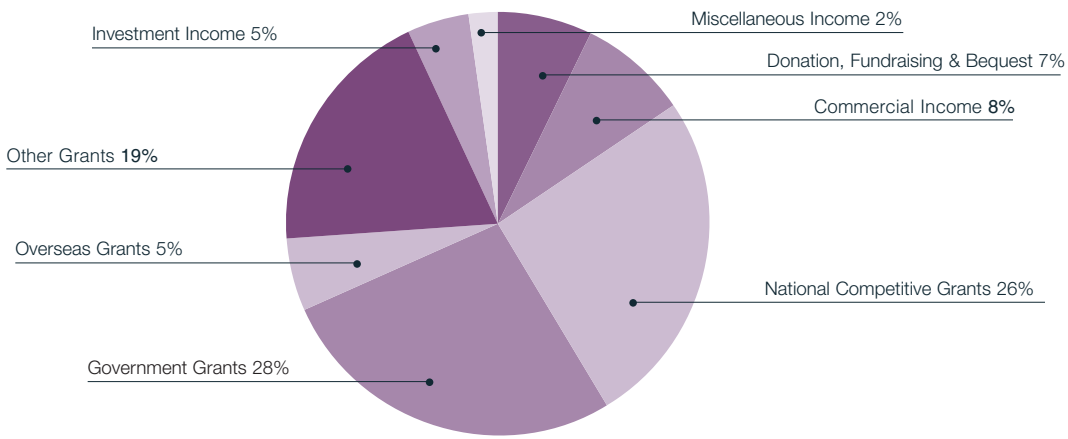
The year in brief

	2002	2001	% Change
Expenditure	18,642,531	14,450,465	29.01%
Number of Staff	283	226	25.22%
Number of Visiting Scientists	15	18	-16.67%
Number of Postgraduates	26	24	8.33%
Total	**324**	**268**	**20.89%**

Expenditure $18.64 million



Income $16.28 million



Research grant income

Commercial Income	
Abbott Australasia	37,668
CSL Limited	73,473
UCB S.A. Pharma	59,994
Gene Stream Pty Ltd	9,896
GlaxoSmithKline	354,971
Pfizer Australia	432,144
Rio Tinto	110,000
Woodside Energy Limited	153,173
Wyeth	33,581
Miscellaneous	1,364
	1,266,264
National Competitive Grants	
National Health and Medical Research Council	4,545,849
	4,545,849
Government Grants	
Department of Health, Western Australia	1,017,472
Disability Services Commission	130,500
Education Department, Western Australia	86,154
Family and Community Services	200,000
Health and Aged Care	889,307
Healthway	413,513
Lotteries Commission	90,000
Medical and Health Infrastructure Fund	44,285
Office of Aboriginal and Torres Strait Islander Health Service	114,940
	2,986,171
Overseas Grants	
International Rett Syndrome Association	52,588
National Institutes of Health	816,919
The Food Allergy Initiative	91,889
World Health Organisation	7,529
Miscellaneous	8,048
	976,973
Other Grants	
Allergy Research Foundation	50,000
Amgen	176,139
Australian Lung Foundation	24,000
Cancer Foundation of WA	170,202
Child Health Research Foundation	35,000
Children's Leukaemia and Cancer Research Foundation	209,708
Cystic Fibrosis Association	75,374
Friends of the Institute	9,375
Ian Potter Foundation	200,000
Kimberley Public Health	3,434
King Edward Memorial Hospital	9,695
Murdoch University	7,300
Princess Margaret Hospital for Children	232,823
Rett Syndrome Association	28,173
Telstra Foundation	40,000
The Baker Foundation	100,000
The Garnett Passe and Rodney Williams Memorial Foundation	37,334
The Smith Family	8,000
Three Boys Legacy	24,760
University of Western Australia	582,014
Variety Club	5,746
Western Australia Institute Medical Research	163,235
Women & Children's Health Service	250,000
Miscellaneous Income	16,544
	2,458,856
Total	**12,234,114**

Donor list and gifting opportunites

Gifting opportunities

"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

Our supporters know that research is costly, but they also know that the health of a child cannot be measured with a dollar amount. They support our work so that all children can be born with the best chance of health, and families will not have to face the heartache of losing a child to illness, disease or disability.

Our supporters are extremely important to us. Your contribution will enable our scientists to carry out the very best research possible under the best conditions available.

For further information about gifting opportunities, please contact the Development Office on (08) 9489 7777 or email development@ichr.uwa.edu.au or visit our website at www.ichr.uwa.edu.au

Donor List

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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Estate Of Jean Isobel Scott
Estate of A Watson
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Jackie Bock
Clifton Hills Primary School
Tania Golding
Sarah-Jane Hombergen
John XXIII College
Kangaroo Ground Primary School
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Little Muppets Child Care Centre
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