



Annual Report ²⁰⁰¹

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Welcome to the Telethon Institute for Child Health Research Annual Report 2001. The Annual Report is a short form overview only. It is designed to give a concise summary of the activities and financial situation of the Telethon Institute for Child Health Research (the Institute) for the year ended 1 December 2001.

The Annual Report does not represent or summarise all the publicly available information about the Institute. Detailed research study reports and financial statements are available through the internet at <http://www.ichr.uwa.edu.au>.

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

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Hope for children and families

Established in 1990 the Telethon Institute for Child Health Research exists to improve the health of children, adolescents and their families.

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

Our major research areas are briefly summarised here. An overview of the research themes in the Institute's seven divisions can be found in the *Divisional Reports* section. Detailed scientific reports are available on our website (www.ichr.uwa.edu.au).



Life on a roll: Telethon boy David Naso, 8, of Inglewood, was overjoyed to meet Chris Mainwaring as he is a keen Eagles supporter. Photo courtesy WA Newspapers

Aboriginal child health page 13

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. This is ground-breaking research and the benefits are both real and long-term.

We are:

- looking at rates of Sudden Infant Death Syndrome (SIDS) which remain high in the Aboriginal population despite a reduction in the general population
- looking at infant care practices in the Aboriginal community
- conducting the Western Australian Aboriginal Child Health Survey.

Asthma, allergies and respiratory diseases page 14

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. It is the most common reason for childhood admission to hospital.

We are working on:

- a vaccine to prevent asthma in high-risk children
- finding out how asthma develops
- better ways to manage, monitor and treat asthma
- house dust mites and how they trigger asthma.

Birth defects page 15

Birth defects occur in one in twenty infants born in Western Australia. Our researchers, along with international groups, have been involved in the research into spina bifida and related severe neural tube defects.

We are working on:

- the impact of folate on a range of birth defects
- a newborn hearing screening program for the early detection of hearing loss in babies
- finding the cause and effects of Rett syndrome
- the effects of in-vitro fertilisation (IVF) programs on mother and child.

Cancer and leukaemia research page 16

Leukaemia is the most common form of cancer in children, accounting for a third of cases. Brain tumours account for a quarter of cases. Treatment for children with cancer has greatly improved over the past forty years, reversing 80 per cent mortality to 80 per cent survival rate.

Our research focuses on the genetic events that lead to cancer and on developing better and less toxic anti-cancer drugs. Both areas depend on understanding the genetic differences between normal and cancer cells. This will in turn change our approach to the diagnosis, classification and treatment of childhood cancer.

Child and adolescent mental health page 17

Adolescent suicide and related child and adolescent mental health problems have been described as an epidemic internationally and Australia has one of the highest youth suicide rates in the world. Our detailed data collection and state population surveys have identified some of the major causes of child and adolescent mental ill health. This information has been used to develop effective early interventions that are now being tested in the community.

Childhood disabilities and death page 18

Cerebral palsy is the most common physical disability in children and affects one in 500 children born in Australia. It can result in partial paralysis, lack of limb coordination, epilepsy and defects in posture, intellect, vision, hearing and speech. Our research has shown that less than ten per cent of cerebral palsy is due to problems during labour. Most causes seem to start earlier in the pregnancy. Our research in this area is recognised worldwide.

We are working to find the causes of:

- cerebral palsy
- newborn encephalopathy (brain disorder)
- intellectual disability
- infant and childhood deaths.

Infectious diseases page 19

Otitis media, or *glue ear*, is very common and can seriously affect speech and hearing, school performance and subsequent social and economic well-being. Its immediate cause may be a viral or bacterial infection in the ear but other factors such as demographics, socio-economic and environmental risk factors also play a role. Our current studies are investigating the most important factors predisposing children to otitis media.

Our other work includes:

- vaccine trials
- virology research into enterovirus and flavivirus encephalitis
- international collaborations on a range of initiatives in population health and infectious disease
- increasing public awareness of and fostering research into meningitis.

Perinatal epidemiology page 20

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 preterm births and growth restriction on a variety of health outcomes.

Research highlights

One of the hallmarks of research excellence is an institution's record of scholarly publications. There have been just over a thousand publications produced by the Institute since its inception in 1990.

Such publications serve not only to inform the academic community of research developments but also to help governments formulate policy and develop appropriate health care programs.

Institute publications have helped to:

- tease out the causal pathways leading to the development of cerebral palsy
- discover the role of folate in the prevention of a class of birth defects – particularly neural tube defects
- uncover the increased risk of birth defects in babies resulting from in-vitro fertilisation (IVF) and intracytoplasmic sperm injection (ICSI) infertility treatments
- describe the extent of sudden infant death syndrome before and after the risk-reducing initiatives were introduced in both the Aboriginal and non-Aboriginal populations
- highlight the morbidity and mortality differences between Aboriginal and non-Aboriginal infants
- outline the benefits resulting from the immunisation of infants against *haemophilus influenzae* – the cost savings for the health system in addition to reductions in mortality, morbidity and disability
- describe the problem of suicide in our society and initiate interventions to reduce this level with quality information for health professionals and the community
- take a multidisciplinary approach to asthma in childhood – molecular and cellular changes, antecedents to developing asthma, genetic and environmental influences, and treatments
- illustrate the benefit of positive parenting and the resilience and vulnerability of children by extensive child health surveys that also look toward possible mechanisms for improvement.

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.

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



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.

Chairman's report

This year provided the Board with the opportunity to assess the progress of the Institute and to plan for the next decade.

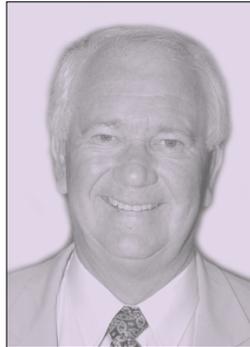
This culminated in December in the formal external peer review chaired by a panel of eminent health and medical research professionals from Australia and overseas. I speak on behalf of the Institute's Board members in saying how delighted we were with the rigour of the review process and with the conclusions of the panel.

A strong message from the review panel to the Institute's Board and senior staff is the importance of securing funding for vital research infrastructure support – from federal and state governments, universities, other agencies and the community. For every dollar of research income we need at least an extra 50 cents to enable the research to proceed.

As the Chair of the International Scientific Review panel Professor Robertson said "This (funding) is vital to the continued success of the Institute, and the benefits that will accrue to child health and well-being from health policies and health interventions that arise from the Institute's research".

A number of initiatives are already in place to address this need.

The Fundraising Committee of the Board is vigorously pursuing the second phase of the capital investment campaign *Give Every Child A Chance*. With a target of \$30 million, more than one third has been realised or pledged already. We are grateful indeed to the Telethon Trustees for their continued commitment to child health research and to the work of the Institute. I am also grateful to members of the committee, Board and others for their time and effort in helping to achieve this target.



A universal theme in the report is the excellence of the Institute and its work. There should be great pride in the knowledge that the panel sees the Institute as a model for child health research and leadership nationally and internationally. In many ways the review recommendations are ones only of minor change or adjustment, and the panel wish the Institute staff to know the overwhelming impression of the panel is of a task being done supremely well.

Professor Don Robertson, Chair of the International Scientific Review panel, in presenting the review report and recommendations to Professor Lou Landau as Chair of the Institute Scientific Advisory Committee, 31 January 2002.

Government commitment to research and to research support is crucial. At a state level the commitment to increased funding for the Medical and Health Research Infrastructure Fund is very encouraging. The creation of the Premier's Science Council is a symbol of the vital role of research and development to the future of Western Australia.

The Board is pleased to support formal agreements with both the University of Western Australia and Curtin University of Technology. This reflects the growing maturity of the Institute and the importance of strong collaborations. Over the past 12 months the Institute has also strongly supported the development of the Biomedical Research and Development Alliance.

Over the years the Institute has nurtured a number of community-based research interest groups. Some of these are located within the Institute, some are not for profit non-government organisations raising vital funds for specific areas of research. I congratulate these groups for their commitment to the work of the Institute.

I wish to thank these volunteers for the major contribution they make to fund raising and as ambassadors for research and for the Institute. Groups like the Friends of the Institute, the Meningitis Centre, the Amanda Young Foundation, the Louisa Alessandri Memorial Fund, the Peter Cameron Memorial Fund, the Children's Leukaemia and Cancer Research Foundation, the Spina Bifida Association, the Variety Club and many others, are vital members of the Institute team.

I am indebted to my fellow Board members and Board committee members for their wise counsel and support over the past year. I was very pleased to welcome to the Board Professor Graham Mitchell who has an outstanding research career and is the Chief Scientist of Victoria. I also thank the members of the Institute Council who elect members of the Board at the Annual General Meeting and who may provide advice to the Board on Institute activity.

May I once again congratulate our Director Professor Fiona Stanley and her outstanding team of staff and students for their exemplary work in the interests of children's health and well-being.

Kevin Campbell AM

Director's report

This has been another great year for the Institute. In 2000, the move to our new building symbolised our coming of age as an institute of national and international standing. This year, our five year International Scientific Review confirmed that our efforts to establish child health as a priority on the national agenda and translate research into action have succeeded.



International Scientific Review

The review is the marker along the road to the Institute maturing into a highly respected, cutting-edge scientific powerhouse setting standards of excellence internationally in the realm of multidisciplinary child health research.

We were very fortunate to attract a superb panel of eminent members with expertise in fields including genetics, epidemiology, Indigenous health, mental health and paediatrics. We are grateful to them for the considerable time and effort they put into the process, both during the week here and afterwards in preparing the reports.

The panel congratulated staff on the series of outstanding scientific presentations included as a major part of the review program and commented:

The Institute has been extremely successful by all national and international standards. The Institute has a research breadth that allows integration of basic science with clinical needs and population health planning. It is held in very high regard by state government agencies, and by its university and hospital partners and collaborators. It has a significant and important role in the national health agenda.

The scientific review provided helpful feedback on our current research agenda and aspirations. The panel applauded the Institute's current research themes and directions. They recognised the value of the Indigenous health initiatives developing within the Institute and acknowledged us as a major national resource in Indigenous health research and training.

They noted the need to attract more infrastructure funding to adequately support both the research activities of the Institute and the plans we are implementing to ensure current and future scientific strength.

Other recommendations centred on the need to consolidate current efforts, to build on our considerable successes and to plan future expansion strategically, particularly in regard to succession planning. We are considering all the recommendations and will work towards implementation. The full document Report of the Scientific Review 10-14 December 2001 is available on our website.



Committees

The Institute continues to provide relevant research to inform and drive strategic government policy. A key element of this work occurs by serving on various committees.

This year in Western Australia I served on the Health Advisory Review Committee, chaired by Mr Mike Daube, which examined the Department of Health's structure and recommended significant reforms.

I also had the privilege to serve on the Premier's Science Council and chair the Health/Information Technology Sub-Committee. The Council has a broad agenda; from encouraging science teaching in schools, right through to research, development and commercialisation. A major issue for us in this State is to achieve and maintain nationally competitive research groups.

Nationally, I again served on the Prime Minister's Science, Engineering and Innovation Council. In June I led a group presentation to the Council to recommend establishing a National Research Partnership for Development, Health and Well-being. This partnership would provide a coherent national agenda for research and evidence to inform relevant policy across portfolios. The Council response was positive – we are now setting up this initiative.

Recognition of research excellence

The Institute continues to be recognised for its successful research in important areas.

A collaboration of principal investigators were awarded a prestigious National Health and Medical Research Council (NHMRC) program grant for their world class research in asthma, respiratory inflammation and allergy (Institute – Pat Holt, Peter Sly, Wayne Thomas, Phil Stumbles; University of Western Australia (UWA) Department of Medicine – John Upham; UWA Department of Paediatrics – Peter Le Souef; NHMRC Fellowship – Steven Stick). With the current NHMRC Program Grant awarded to the Population Sciences Division for epidemiological studies in maternal and child health, the Institute joins the ranks of highly regarded Australian institutes in health and medical research.

The Children's Leukaemia and Cancer Research Division has won four prestigious National Institute of Health grants this year. These included funding for Professor Ursula Kees' ground-breaking work in identifying molecular and other techniques to provide a more precise diagnostic accuracy and stratification of risk for patients with childhood leukaemia; and for Dr Paul Watts' work in genetics, DNA topology and molecular oncology.

The Western Australian Institute of Medical Research Cancer Biology laboratory headed by Professor Glenn Begley moved into the Institute in April. This has benefited cancer research within the state and collaborations are being further developed within the Institute.

The Epidemiology area has continued to forge important community links, for example, with St Mary's Anglican Girls' School and the Rett study. It has also been awarded a NHMRC grant to continue research into outcomes of fertility treatments. Congratulations to Prof Carol Bower for winning the Public Health Association Individual Community Award for research into folate and the prevention of neural tube defects.

On 24 July the Western Australian Minister for Health Bob Kucera launched the Drugs and Suicide Report at the Institute. The extensive media coverage ensured the issues were thoroughly disseminated to the community. In August, the Institute's contribution to the state Drug Summit emphasised the importance of early intervention strategies in the prevention of substance misuse. This state has the second highest incidence of recent illicit drug use in Australia and the statistics for our young people are disturbing.

In September, the Institute hosted the Kulunga Open Day Forum to inform Indigenous groups about our results in Indigenous maternal and child health research. The day was an outstanding success with good local attendance and national and international guest speakers. Cathy Freeman, Patron of the Kulunga Network, visited the Institute in October.

The results of the Positive Parenting Program, a population intervention designed to prevent child behavioural problems in vulnerable families, were released in October. This evaluation has influenced state government parenting policies.

Regular reports of the Institute's activities appear in local, national and international media. It is important we develop good relationships with the media – we need to inform parents and the broader community about health issues and what our research means for them.

The Institute's standing in the community, which influences our supporters, needs to be carefully portrayed by journalists who understand the importance of our work. The Institute has been very fortunate to obtain the services of consultant Ms Elizabeth Chester to coordinate our media contacts. She has done an excellent job – her advice and expertise has been invaluable.

Collaborations

Partnerships across disciplines and sectors that emphasise inclusiveness, pooling of information and resources have been a major theme of our activities and achievements over the past year.

The Western Australian Aboriginal Child Health Survey shows the potential of innovative partnerships with funding bodies and with the communities involved in the survey. I believe this survey will be recognised internationally because of its scope and high participation rate – a 90 per cent response rate and a sample size of 5200 Aboriginal children across the state.

The Institute continues its commitment to the Biomedical Research and Development Alliance. This exciting cross-sectoral venture will involve biomedical research institutes across the state, industry, universities and government. It aims to establish Western Australia as an internationally recognised centre of bioinnovation. One of the major challenges is to ensure adequate resources to support the infrastructure needed to implement the objectives of the Alliance. The state government has provided funding for this important initiative. Ongoing support by government and industry is crucial the success of the Alliance.

The Centre for Developmental Health was established as a joint venture between Curtin University of Technology and the Institute. It aims to conduct research in developmental health, to apply research results and to provide a research training focus in this important area. Professors Stephen Zubrick and Sven Silburn are co-directors and I serve on the Board with Professors Charles Watson (Dean of Health Sciences, Curtin University) and Ann Sanson (Scientific Director, Australian Institute of Family Studies).

The Collaboration for Applied Research and Evaluation (CARE) was started within the Institute this year, funded by the Western Australian Department of Health. CARE serves two key purposes. The first is to support internal research groups by promoting demonstration research programs where applicable, and supporting statewide implementation where recommended. The second is to increase research uptake, through advocacy and promotion of the Institute internationally and nationally as a developmental health research centre of excellence. CARE will play a vital role in brokering partnerships between the Institute and funding partners.

The Institute is working closely with the University of Western Australia to establish a Centre for Child Health Research to enhance our collaborations and for other mutual benefits. How this may fit into the University's new school structure will be considered through 2002/03.

I am grateful to our staff, Board and numerous colleagues and collaborators for their hard work, advice and immeasurable contributions to the on-going success of the Institute. I would also like to thank our donors for their generous support. In particular I would like to thank Telethon for continuing to be our major sponsor.

As a special acknowledgment may I thank Ms Lucy Henry for fully donating her services to edit and coordinate the production of this annual report.

I look forward to another challenging and exciting year.

Fiona Stanley AC

Senior staff



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 with Coopers and Lybrand also in London.



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 of Australia and holds a Professorship at the University of Western Australia. Previous appointments include Acting Director, Clinical Immunology Research Unit, Princess Margaret Hospital; and Research Fellow, Institute of Environmental Hygiene, University of Gothenburg.



Wayne Thomas

BSc Hons PhD

**Member of Executive, Head of Laboratory Sciences,
Head of Division Molecular Biology**

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 past chair of the International Allergen Nomenclature Committee; NHMRC grant review panel for inflammation, allergy and haematology.



Peter Sly

MD FRACP

Member of Executive, Head of Clinical Sciences

Prof Sly set up 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.



Stephen Zubrick

MSc MA PhD

Member of Executive, Head of Population Sciences

Prof Zubrick completed his doctoral and postdoctoral work in psychology at the University of Michigan. Before starting at the Institute in 1991 he worked in Western Australian hospital and outpatient health and mental health settings for many years. He is currently Professor, Centre for Developmental Health, Curtin University of Technology.



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

Adjunct Professor University of Western Australia, Prof Begley is interested in the mechanisms controlling normal blood development, and how deregulation of these processes causes leukaemia. He identified the Stem Cell Leukaemia (SCL) gene which is absolutely required for embryonic haematopoietic development as well as being involved in vasculogenesis and possibly in brain development.



Carol Bower
MBBS MSc PhD FAFPHM DLSHTM
Head of Division Epidemiology

Adjunct Clinical Associate 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 Commonwealth and State Governments. He has coordinated two five yearly international reviews and the planning and opening of the Institute new building.



Ursula Kees
PhD
Head of Division Leukaemia and Cancer Research

Adjunct Associate Professor (University of Western Australia)



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 a Clinical Senior Lecturer of the Department of Microbiology, 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.



Research reports

Aboriginal child health

The rates of illness and death among Aboriginal children are higher than those of non-Aboriginal children.

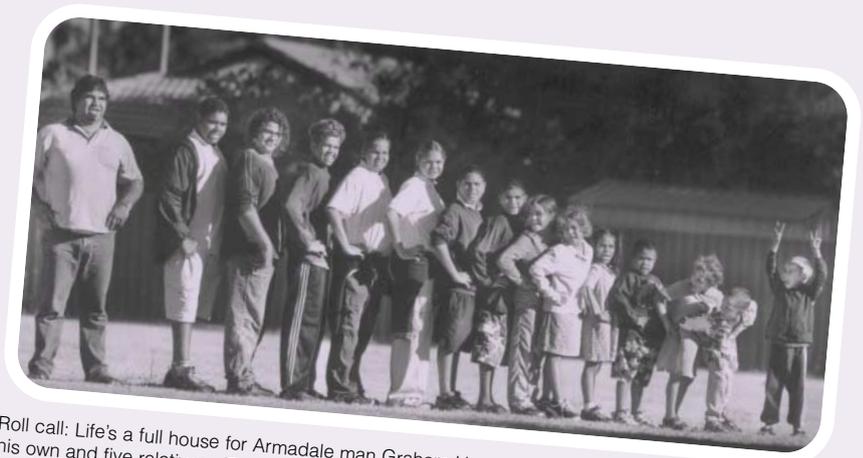
The Institute stands firmly for Aboriginal empowerment. It is committed to training, informing, giving skills and knowledge in research and health needs, and outcomes to Indigenous researchers. The Institute employs Aboriginal health workers in its research programs.

The Kulunga network

Kulunga is a collaborative maternal and child health research network project involving the Institute and member services of the Western Australian Aboriginal Community Controlled Health Organisation. The stimulus for Kulunga came from the Bibbulung Garneep (Solid Kids) home and community visiting program. Kulunga is the Nyunga word for children.

An executive committee made up of representatives from the current interested partners who meet quarterly directs the Network. These include the Child Health Research Foundation, Western Australian Aboriginal Community Controlled Health Organisation, the Derbarl Yerrigan Health Service and the Institute. There is also an internal management-type arrangement where projects within the Institute under the scope of the network can raise and discuss issues and provide project updates.

Research is planned in relation to Fetal Alcohol Syndrome, dental health, use of pamphlets in health education, renal disease, and pregnancy intervention.



Roll call: Life's a full house for Armadale man Graham Hansen. He's a dad to 14 children – nine of his own and five relatives. The Hansen family is a participant in the Institute's Western Australian Aboriginal Child Health Survey. Photo courtesy WA Newspapers

Western Australian Aboriginal Child Health Survey

Consideration of the Western Australian Aboriginal Child Health Survey began in the early 1990's, at the same time as the Western Australian Child Health Survey. However on the recommendation of an Aboriginal reference group it was not started until later.

After the release of the findings of the successful Western Australian Child Health Survey, this survey proceeded. It has involved 130 field staff, approximately half of whom were Indigenous, and a sample size of 5200 Aboriginal children across the state with a 90 per cent response rate.

The information gathered is now being analysed. Results are expected to be progressively released from mid 2003.

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 a world leader in research for drugs to treat asthma. We are focusing on how asthma develops, better ways to manage and monitor asthma, and new treatments for asthma.



Complications: Professor Wayne Thomas focused on allergens at the National Asthma Conference in Fremantle. Photo courtesy WA Newspapers

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 currently no known cure for cystic fibrosis. Important future research directions for cystic fibrosis include developing non-invasive ways to measure lung inflammation and predicting and preventing early lung damage.

Birth defects

Spina bifida

Our researchers, along with international groups, have been involved in the research into spina bifida and other 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 preventative program in collaboration with the then Health Department of Western Australia. The rate of babies born with spina bifida began falling in 1996 and is now 30 per cent less than before the health promotion project began.

We are currently investigating the role of folate in preventing in other birth defects such as heart, limb and urogenital defects.

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 early in order to start treatment by six months of age. Newborn hearing screening involves a set of tests that are done prior to a baby's discharge from the maternity hospital.

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 show a lot of individual difference in the severity of the

disability, although all are incapable of living on their own and need constant care.

The Institute maintains a national register of people with Rett syndrome. Our database records functional ability, health problems, medication use, therapy and education services.

This information is extremely useful to parents and doctors who have previously been unable to access up to date information about the disorder.

Since the discovery of the gene responsible for Rett syndrome in 1999 we have identified the presence of the genetic abnormality in about two thirds of these cases. We are now examining how different gene mutations may impact on the health and physical ability of those affected in order to identify any patterns.

Births after assisted conception

Our previous research has shown that infants conceived with assisted conception techniques had twice the risk of a major birth defect compared to naturally conceived infants.

A new study will examine admission to hospital, cerebral palsy, intellectual disability and birth defects diagnosed up to the age of six years in a larger sample of assisted conception infants, compared to the remainder of Western Australian births.



Lessons for doctors: Elise Bozsán with some of the St Mary's students in the Rett syndrome study, clockwise from left, Emily Gordon, Samantha Tennant, Alana Knogras and Kelsey Douglas. The students will provide information for comparison with syndrome sufferers. Photo courtesy WA Newspapers

Cancer and leukaemia research

Leukaemia is the most common form of cancer in children, accounting for a third of cases, followed by brain tumours diagnosed in one quarter of cases. Treatment for children with cancer has greatly improved over the past forty years, reversing 80 per cent mortality to 80 per cent survival rate. However, despite tremendous improvements in therapy some children still experience relapse.

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

The research focuses on the genetic events leading to cancer and on developing better and less toxic anti-cancer drugs. Both areas depend on understanding the genetic differences between normal and cancer cells. This will in turn change our approach to the diagnosis, classification and treatment of childhood cancer.

One area of our research aims to understand more about the control of blood cell formation and the development of leukaemia. We have discovered one gene that is very important in both these processes. It is the most common genetic abnormality involved in causing human T-cell leukaemia and we have shown that it is absolutely required for the development of all blood cells. We are working toward understanding how a gene important in blood cell formation can also be important in causing leukaemia.



Winner: Institute of Child Health Research young investigator of the year Tina Carter is congratulated by Leukaemia patient Dejan Gajic, 10. Dr Carter is continuing her leukaemia research in Canada. Photo courtesy WA Newspapers

Child and adolescent mental health

Adolescent suicide and related child and adolescent mental health problems have been described as an epidemic internationally and Australia has one of the highest youth suicide rates in the world.

We are also seeing epidemics of risk taking behaviours, attention deficit hyperactivity disorder (ADHD), depression and eating disorders. Researchers in education and the social sciences are observing similar increases in developmental problems in children and young people (behavioural problems, learning disabilities, school drop-out) and juvenile crime.

The challenges facing our Institute and others committed to improving child and youth health and well-being are enormous. Over the last 30 years we appear to have created toxic societies that are having detrimental effects on a variety of outcomes for children, families and societies generally.

Some research suggests a commonality of pathways to these problems. If the earlier factors in the pathways were known then preventative strategies may reduce a number of these problems.

Our detailed data collection and state population surveys have identified some of the major causes of child and adolescent mental ill health. This information has been used to develop effective early interventions now being tested in the community.

Our research in this area includes evaluating the:

- state-wide rollout of Aussie-optimism – a program aiming to prevent depression by teaching skills in positive thinking, problem solving, negotiation, relaxation and assertiveness to children as they enter puberty
- Western Australian implementation of Positive Parenting for Preschoolers (Triple P) through child care facilities. 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 a predominantly negative style of parenting.

Childhood disabilities and death

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 are due to problems during labour. Most causes seem to start earlier in the pregnancy. Infections during pregnancy and preterm births play a more significant role.

Our research into the causes of cerebral palsy in term and preterm babies is recognised worldwide. Our research is also relevant to families living with the problems of cerebral palsy.

Newborn encephalopathy

Newborn encephalopathy, or brain disorder, occurs in around one in 300 births. It refers to full term babies who become ill or behave abnormally soon after birth. 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 is looking at how newborn encephalopathy affects children as they grow to adulthood.



Standing tall: Sophie Manning, 3, shows her style with a walking aid to Dr Eve Blair, left, and Professor Fiona Stanley. The WA scientists have won accolades for their cerebral palsy research. Photo courtesy WA Newspapers

We are also examining the causes of this condition with the possibility of a cure or prevention in the future.

Intellectual disability

Our research focuses on finding the causes of intellectual disability and whether the causes change over time. Our current work is measuring the frequency of intellectual disability in Western Australia by collecting data from a variety of different sources.

Infant and childhood deaths

We have developed a complete mortality profile for Indigenous and non-Indigenous Western Australian infants and children from 1980 to 1998. The profile includes geographical information describing place of death (in or out of hospital) and residence at time of death. These data will help to identify communities or areas where children are at increased risk of death with the aim of designing programs and providing health services that are community rather than hospital based.

Infectious diseases

Otitis media

Otitis media is an infection or inflammation of the middle ear. This condition, often called *glue ear*, may persist for many months. It can significantly affect a child's hearing and consequently impair speech, language development and learning.

Our research in this area is looking at:

- risk factors for otitis media
- ways to help reduce and treat otitis media in Aboriginal children
- the impact of introducing swimming pools on the prevalence of ear and skin disease and general well-being in Aboriginal children living in remote communities.

Virology research

Our work in this area has the ultimate aim of developing genetically defined, live attenuated vaccines for:

- Murray Valley encephalitis and Japanese encephalitis – potentially fatal mosquito-borne diseases of the Asia-Pacific region
- Enterovirus 71 – a gastrointestinal virus that can cause paralysis in toddlers.

Vaccine trials

The Institute collaborates with Princess Margaret Hospital and the University of Western Australia Department of Paediatrics to coordinate the approach to the development, delivery, assessment of efficacy and promotion of vaccines in our community.

Our goals are to:

- develop a specialised immunisation service to provide expert advice on using vaccines for special risk groups, dealing with potential adverse reactions to vaccines and community concerns regarding immunisation
- explore the safety of current and future childhood vaccines
- identify genetic influences on the immune response to vaccines and infectious diseases
- conduct better surveillance of vaccine preventable diseases, illness and associated cost to inform immunisation policy.

International collaborations

The Institute is a member of the Buttrressing Coalition of the Papua New Guinea Institute of Medical Research. Collaborations between the institutes may include a range of initiatives in population health and infectious disease such as training, demographic studies, immune responses to vaccines and asthma.

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.

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 preterm birth and growth restriction on a variety of health outcomes.

The Western Australian Twin Child Health Study (WATCH)

This major study uses data on all multiple births between 1980 and 1994. It is the only population based twin study in Australia.

When it started in 1997 the main aim of the study was to investigate the roles that genes and the environment play in the development of asthma and allergies. It also studies early language development and child temperament.



Finger on community pulse: Lifelong Raine Study participant Jasmine O'Brien, 10, with her mother, Julie. Photo courtesy of WA Newspapers

The Western Australian Pregnancy Cohort (Raine) Study

Approximately 3000 women in early pregnancy were enrolled into this study – 2400 children remain in the study after ten years of follow up. Assessments of the children have been carried out at ages one, two, three, five and a half, eight and ten years.

This study is providing extremely valuable information on factors that occurred during the pregnancy, any life factors and environmental factors that impact on the development of later disease.

Further funding is needed to enable the children to be followed into adulthood.

Divisional reports

Cancer biology

Cancer is caused by the dysregulated or uncontrolled growth of cells. There are two key elements to this process. One is the mechanisms that go awry within the cell itself, and the other is the result of the signals that the cell receives from its external environment. We are interested in both these processes.

In terms of the problems that can occur within a cancer cell, our studies focus on a key molecule that is critical in the development of human T-cell leukaemia. This molecule, which we discovered, is called the Stem Cell Leukaemia (SCL) gene and is involved in up to 60 per cent of cases of this devastating childhood disease. In these cases it is aberrantly 'turned-on' in cells where it should normally be silent. We seek to understand the mechanisms by which it causes leukaemia in the hope that it informs our attempts to develop new therapeutic approaches. To this end, we must also understand the normal function of this gene: we know that it is also critically important in the normal formation of all blood cells and blood stem cells in particular, but we know little about how it exerts this effect. To address this, we are seeking to identify the genes through which SCL acts (so called 'target genes'). SCL also has a function in the brain about which nothing is known. Obviously we also need to understand this if we ever hope to turn the SCL gene off in cells. Our studies on SCL are closely integrated with similar work taking place within the Institute.



Our studies on the signals a cell receives from its environment are examining a growth factor (or hormone) that we discovered causes breast cancer cells to stop growing. This growth factor is called Oncostatin M (or OSM). Again we need to understand both the normal function of this growth factor and how its action on cancer cells can be exploited to therapeutic advantage. Our studies are designed to address both these important questions.

Detailed reports of the division's activities may be found on our website at www.ichr.uwa.edu.au.



Cell biology

Our principal research theme is the elucidation of mechanisms that underlie the initiation and progression of inflammatory diseases of the respiratory tract, with particular emphasis on asthma.

This work involves a series of integrated research projects using material from both experimental animal and human sources. The former studies focus upon mechanism(s) responsible for regulation of T-cell mediated immune responses in respiratory tract tissues and associated regional lymph nodes. Of particular interest are populations of Dendritic Cells (DC) in respiratory tract tissues, especially within the conducting airways, which we have identified in earlier work as the principal resident antigen presenting cells in these tissues. It is clear from our studies that the DC regulate the intensity and duration of local immune responses to inhaled antigens, which include not only environmental allergens but also viral pathogens, and they also determine the nature of ensuing programming of immunological memory.

Our second major research stream focuses upon postnatal development of T-cell immunity to environmental antigens in humans, in particular airborne allergens relevant to asthma pathogenesis. We have previously described an important genetically determined deficiency in postnatal maturation of Th1 function in children at high risk for atopy, which we believe increases susceptibility to allergic sensitisation and also to respiratory viral infection. We have also recently collaborated with the

Martinez group in the US in the identification of a polymorphism in the CD14 gene which is associated with intensity of allergy, and which may also be involved in the Th1 maturation defect referred to above. We additionally have a rapidly growing interest in paediatric vaccine immunology, and in particular in the role of developmental-associated variations in immune function as determinants of vaccine responsiveness.

Detailed reports of the division's activities may be found on our website at www.ichr.uwa.edu.au.



Children's leukaemia and cancer research

Leukaemia is the most common form of cancer in children, accounting for a third of cases, followed by brain tumours that are diagnosed in 25 per cent of patients. The Oncology Total Care Unit at the Princess Margaret Hospital (PMH) and our research laboratory maintain a close relationship and we are members of the largest study group into childhood cancers, the US-based Children's Oncology Group (COG).

Despite tremendous improvements in therapy, some patients still experience relapse. Our research focuses on the genetic events that lead to cancer formation and on the development of more effective and less toxic anti-cancer drugs. Both areas depend on a better understanding of the genetic differences between normal and cancer cells. This in turn will change our approach to the diagnosis, classification and treatment of childhood cancer.

The research program of the division comprises four areas:

- Gene expression profiles in childhood acute lymphoblastic leukaemia (ALL), where we make use of the novel microarray technology. The HOX11 oncogene is of particular interest. It was discovered at a chromosomal breakpoint in one of our cell lines from a patient diagnosed with ALL of T-cell type (T-ALL). HOX11 is a DNA-binding oncoprotein aberrantly expressed in a significant proportion of T-ALL patients. Our recent studies confirm that HOX11 deregulation occurs in the absence of any translocation, hence other mechanisms must cause gene activation and these are currently under investigation. We have employed various approaches to identify genes whose expression is altered by HOX11.

- In previous work we showed that deletion of the tumour suppressor gene p16 is associated with unfavourable outcome in paediatric ALL. Our most recent studies were conducted using real-time polymerase chain reaction (PCR) which confirmed and extended these findings. This method is a precise high-throughput assay with applications in a wide range of cancers.
- A new research program focuses on paediatric brain tumours. The major aim is to identify tumour suppressor genes by using representational difference analysis in combination with array technology.
- Our research is targeted at the development of new approaches to find anti-cancer drugs. The current project aims at developing a platform technology for isolating specific peptide inhibitors of oncoprotein interactions. The study provides the groundwork for a high-throughput screening system for novel peptide-based drugs.

Detailed reports of the division's activities may be found on our website at www.ichr.uwa.edu.au.



Clinical sciences

We aim to conduct high quality, clinically oriented research that focuses on paediatric respiratory diseases, especially asthma, cystic fibrosis and vaccine preventable disease. We have five subgroups loosely based around different methodologies.

The **Infant Lung Function Group** works to develop and apply new techniques for measuring lung function in infants up to the age of two years. These new techniques measure the growth and development of airways and lung tissues, determine the site of action within the lungs of asthma drugs and determine whether lung function abnormalities predict which infants will have persistent asthma.

The **Respiratory Physiology Group** uses sophisticated measurements of lung function in small animals to investigate: structure-function correlates in animal models; mechanisms of atopic sensitisation, bronchial responsiveness and asthma; the role of virus infections in altering lung structure and function; and mechanisms of inflammatory damage to lungs in animal models of human lung diseases.

The **Cystic Fibrosis Group** studies the mechanisms underlying the host inflammatory response in cystic fibrosis as well as issues related to diet, growth and nutritional requirements. The group also develops strategies to prevent progressive lung damage in this condition. Laboratory-based techniques, animal models and clinical methodologies are used to conduct multidisciplinary research in close collaboration with the Cystic Fibrosis Clinic at Princess Margaret Hospital for Children.

The **Clinical Asthma Research Group** conducts projects involving infants and children with asthma. Projects focus on the mechanisms underlying the development of asthma and on better methods for managing, monitoring and treating asthma. This group runs a number of cohort studies looking at the antenatal antecedents of asthma, the influence of infections on the development of allergic sensitisation and the genetic basis of asthma.

The National Health and Medical Research Council grant for the Developmental Aspects of Respiratory Inflammation, Allergy and Asthma collaborative study was a highlight of the year. This gives the asthma program secure funding for the next five years and will act as a platform for major advances in our research in this area.

The **Vaccine Trials Group** is a collaborative venture between our division, Princess Margaret Hospital for Children and the University of Western Australia Department of Paediatrics. The group performs phase 1, 2 and 3 trials with new vaccines, conducts trials into non-vaccine treatments of vaccine-preventable diseases and conducts research into the development of immunity to vaccines and vaccine-preventable diseases.

Detailed reports of the division's activities may be found on our website at www.ichr.uwa.edu.au.



Molecular biology

The research in the division concentrates on the molecules that cause allergic sensitisation and the development of immunotherapy to prevent and treat allergic diseases, especially asthma. The scope of the investigations extends from the molecular characterisation of allergens and allergic responses to the production of modified allergens and molecular mimics for new therapies.

The study of indoor allergens has broadened from the house dust mite, to the next most prevalent source, the cat. This new direction has been driven by critical developments in the study of cat allergy especially the implementation of clinical trials with peptide-based immunotherapy and the discovery that tolerance to cat allergens can be induced by high dose exposure during infancy. The spectrum of allergenic specificities produced by the cat, and how the responses to individual allergens interact, has however remained virtually unexplored. Our studies with molecular cloning have identified several unrecognised allergens that are under investigation in the contexts above. One of the allergens is a major IgE-binding specificity. The study of house dust mite allergens has continued with the main aim of identifying major allergens and antigens that induce sensitisation, and, for non-allergic subjects, protection. The measurement of T-cell cytokine responses to a panel of recombinant allergens has shown the importance of the group 1 and 2 allergens for inducing Th2 cytokines and suggest that immunotherapy should be based on these molecules. Other allergens which have been difficult to clone or produce, or have only recently been identified, are however being studied further. One of these which has been studied this year is the amylase allergen which

has isoforms encoded by two divergent genes. While the major group 1 and 2 house dust mite allergens are products of single genes a feature is their high degree of allelic polymorphism. It is possible that the sequence variation may be a factor that enhances allergenicity and, less speculatively, information on the variants is required to develop genetically engineered allergens. Recombinant proteins made from different alleles of Der p 2 have now been examined for antibody binding and their ability to stimulate T-cell cytokine release. While some interesting effects of amino acid substitutions were evident, a very practical result was to identify that the combination of the two most divergent alleles can represent the allergen for therapeutic formulations based on recombinant allergens.

The structural information and recombinant allergens are being obtained principally to develop new types of immunotherapy. As well as providing critical information and reagents for other research laboratories and collaboration with pharmaceutical companies the division has been investigating several potential therapies. The intranasal administration of peptides containing T-cell epitopes of allergens has been shown to protect mice from making IgE hypersensitivity responses to the whole allergen. This has potential for immunotherapy, but follow up studies have shown that regimens that block allergic reactions to the injection of allergen do not inhibit responses to inhaled allergen. Indeed they can even enhance pulmonary inflammation. A critical strategy has therefore been to study animal models that induce allergies by inhalation rather than the more convenient models used in other laboratories that inject the allergens.



In addition to therapy based on genetically engineered allergens, a new strategy is to use of unrelated peptides that mimic the shape of the allergens. This mimotope technology is being studied with an allergen in a mouse model using mimetics isolated with monoclonal antibodies shown to be able to inhibit sensitisation. The studies are examining mimetics derived from the classical random combinations of amino acids and a new mimetic strategy based on a phylogenetically diverse biological source of peptides. A combination of genetically engineered T and B-cell epitopes is thus being studied to develop more efficient and safe methods of improving immunotherapy.

Highlight

Genetic diversity of house dust mite allergen – polymorphisms rationalised.

Recombinant allergens provide a gateway to the development of new types of immunotherapy for asthma. The sequence analyses of the major house dust mite allergens have however revealed a great deal of genetic diversity or polymorphism, even within mites in the same home. This has raised the possibility that a complex mixture or recombinant molecules may be required to adequately represent the natural allergens. We have shown that the major Der p 2 allergen of house dust mites has diversified along two genetic pathways involving changes in a cluster of residues that affect the antigenicity. It has now been shown that only two recombinant allergens that contain all the most abundant genetic changes are required to represent the diversity of Der p 2 for therapeutic preparations.

Detailed reports of the division's activities may be found on our website at www.ichr.uwa.edu.au.



Population sciences

The research program for the division is focussed principally in three broad areas:

- documenting the burden of disease in children and young people
- assessing the causal pathways that lead to disease or health
- assessing the significance of these findings for the prevention of disease and/or the promotion of health.

The Division of Population Science comprises 132 staff and students. Its scientific work is carried out by project teams working in epidemiology, biostatistics and computing, genetic epidemiology, psychosocial sciences, and through extensive collaborations with government and non-government sectors. While there is a large diversity in the range of issues we study, particular foci include asthma and atopy, cancer, developmental disorders and innovative methodologies.

During 2001 several achievements should be noted.

- Dr Deborah Lehmann and her team launched their findings on a study of the relationship between the provision of public swimming pools in remote Aboriginal communities and the occurrence of otitis media in children. The preliminary findings are encouraging and have attracted considerable national interest.
- A new area of epidemiological research into childhood cancer commenced in response to the unexpected finding of a reduction in the risk of acute lymphoblastic leukaemia associated with maternal folate intake.
- A five-day course on data linkage was hosted in collaboration with the University of Western Australia Department of Public

Health. The course was organised and presented by Professor D'Arcy Holman, a leading expert and proponent of the use of data linkage to address key questions in population health, genetics and preventive medicine.

- A new Australian study showing that babies conceived through assisted conception procedures are more than twice as likely as naturally conceived infants to be diagnosed with major birth defects in their first year of life was published by Drs Carol Bower, Jennifer Kurinczuk, Sandy Webb and Michèle Hansen.
- The division hosted Professor Martha Werler, Fogarty Senior International Visiting Fellow, from the Boston University Slone Epidemiology Unit during her sabbatical. Professor Werler, an epidemiologist, is well known for her research on birth defects and has a particular interest in the effect of medication use in pregnancy.
- A contract management team was established to assist in developing and maintaining the contract environment through which many of our research services and outputs are purchased. Operating under the title of Collaboration for Applied Research and Evaluation (CARE), the CARE team ensures an accountable contract environment with State and Commonwealth Governments and private sector purchasers that is in line with the Institute's mission and aims.

Detailed reports of the division's activities may be found on our website at www.ichr.uwa.edu.au.



Virology

The division was recently set up to provide a nucleus for the development of research into infectious diseases of significance in childhood.

The diseases being studied are Murray Valley encephalitis, Japanese encephalitis and enterovirus encephalitis.

Our current research focuses on understanding how viruses cause disease within the central nervous system (CNS). This research covers a wide range of activity, including molecular studies of viral replication, studies of the pathogenesis of viral encephalitis using animal models, the development of community surveillance for viruses causing CNS infections and the development of improved diagnostic methods.



Detailed reports of the division's activities may be found on our website at www.ichr.uwa.edu.au.





CHILD
HEALTH
RESEARCH

Board of Directors



Kevin Campbell AM
Chairman,
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) Hon D.Sci(Curtin)

Director General, Department of Health; previously Chief Executive Officer, Cancer Foundation of Western Australia



Keith Jones
Bbus A.C.A. CPA

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



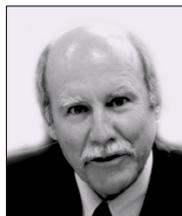
Louis Landau AO
MD FRACP

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



Rebecca Maslen-Stannage
LLB(Hons) BComBCL(Oxon)

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*

Scientific Director, Telethon Institute for Child Health Research; Variety Club Professor, Department of Paediatrics, 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 support the Board by offering advice in specific areas.

Appointments and Promotions Committee

Mike Daube (chair until December 2001)
Kevin Campbell AM (chair from January 2002)
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
Bruce McHarrie
Michale Matthews
William Rayner
Fred Stone
Fiona Stanley AC

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
The Hon Richard Court
Paul Davis (from April 2002)
Mike Daube (until November 2001)
Tammy Gibbs
Bruce McHarrie
Maurice Swanson

Intellectual Property Commercialisation Committee

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

Scientific Advisory Committee

Lou Landau AO (chair)
Colin Binns
Harvey Coates
Cathy Cole (to December 2001)
Angela Alessandri (from January 2002)
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

It has been a year of significant growth at the Institute – total income increased approximately 25 per cent compared to the previous year, with permanent staff numbers up 31 per cent and a comparable increase in the number of research projects. This translates into a significant increase in transaction volume and tests our people, systems and procedures. It therefore seems appropriate that strategic planning, to ensure we can address future demands, was a key feature this year.

The highlight of several strategic planning events was the International Scientific Review of the Institute in December. The planning and preparation for the review commenced months beforehand. Through a process of consultation involving staff, the executive and the Board, the Institute reviewed its own performance; its standing in the medical research community locally, nationally and internationally; existing strategic directions and factors likely to impact on future plans.

The week-long review looked in depth at our research activities, our size and structure, management, succession planning, funding, external collaboration and much more. The panel's report was extremely complimentary towards our achievements. It identified a number of future challenges and made many relevant recommendations.

A particular emphasis was placed on infrastructure funding. The Western Australian Government was applauded for establishing its medical research infrastructure fund but the panel highlighted the fact that it falls well below the level in Queensland and New South Wales. This puts us at a competitive disadvantage nationally and internationally. The returns to

Government of investing in infrastructure are large, particularly in areas of research that influence evidence-based health policy – we must continue to lobby for increased funding.

The review provided much information and many recommendations about our future direction. Early in 2002, it will be crucial to consolidate this information and set priorities and plans for the next five years.

Funding is a critical factor. Whilst government funding is always important, we cannot depend on that source alone – raising our own capital reserves is vital. We aim to lift our capital fund to \$30 million, an increase of approximately \$20 million. A fundraising committee of the Board has been established comprising selected Board members and other long-standing advocates of the Institute, most notably, The Hon Richard Court. We have already taken a significant step towards our new target with Telethon reconfirming their ongoing support.

Complementing the strategic planning is our continuing involvement in the Biomedical Research and Development Alliance. The Alliance is a collaboration of biomedical research institutes, universities, industry and government to develop Western Australia into an internationally recognised centre of bioinnovation.

This year, Alliance activities focused on increased collaboration within the medical research community and increased liaison with government. In 2002, we will appoint an executive officer to the Alliance to further develop and implement its activities. There will be an increasing focus on interaction with government.

For the first time, the Biomedical Research and Development Alliance will be an exhibitor at the BIO 2002 conference in Toronto, providing exposure at the international level. Under the banner of the Alliance the Institute will also have the opportunity to promote itself at this conference.

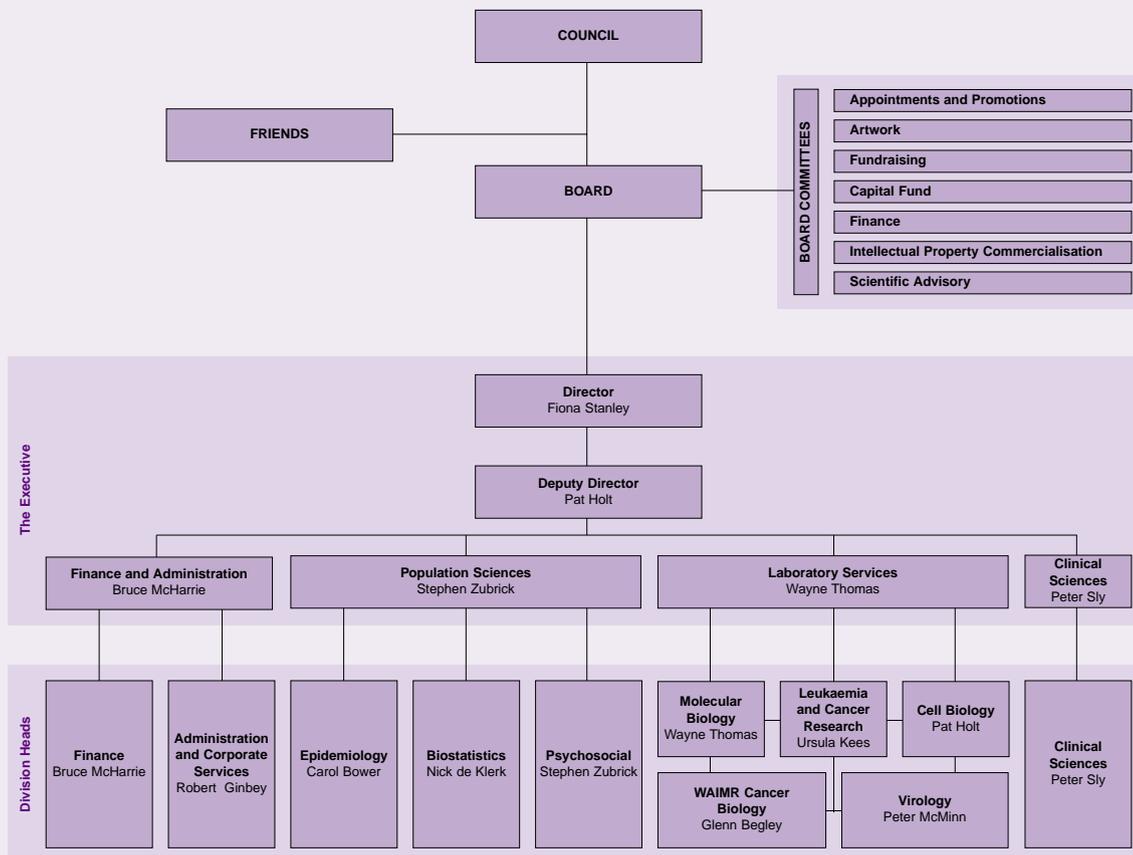
The Institute is giving increasing attention to exploring commercial opportunities for its research. To guide this effort an Intellectual Property Commercialisation Committee was established during the year. This coincided with the appointment of Professor Graham Mitchell AO to the Board in March. Prof Mitchell is the chief scientist of Victoria and also operates Foursight Associates, a Melbourne-based organisation that assists companies commercialise their technology. He is therefore, ideally placed to assist the Institute.

This is just a sample of some of our initiatives that will ensure the Institute's longevity and productivity. Underpinning such initiatives are the current research projects, the related personnel and the administrative support team.

I acknowledge the efforts and commitment of my administrative team who have continually ensured the smooth functioning of the Institute's support systems to a standard envied by many other organisations.

Bruce McHarrie

Management/Operating Structure



Administration and corporate services

This year saw the fine-tuning and implementation of the Management Information System. The new system provides vastly improved technology for management reporting and accountability, and timely and comprehensive strategic management information. It will integrate information from finance and accounts, human resources and payroll, facilities management and can be linked to web-based operations and reporting.

Such a major investment does not come without cost. Testing and implementing the new system has been an arduous exercise – the benefits however will be significant. On behalf of the Institute I wish to thank the managers and staff at the cutting edge of this change and to acknowledge their contribution.

It was also a year for consolidation. After the honeymoon period of the new building opening in 2000, came the hard grind of managing and finding the budget for a fully operational building. This begins a long-term commitment to maintaining the building and its facilities and providing for the regular replacement and upgrading of high technology equipment. Given the constant demand for office workstations it is already time to explore the next phase of the Institute's building program.

The corollary of this, as was well recognised in the International Scientific Review, is the importance of our people. Excellence in human resource management will contribute to excellence in research. In this respect the three major tenets of the administration team are: state of the art human resources policies and practices for all of our people including students; effective internal communication; and vigilance in risk management including occupational safety and health.

We were all very pleased with the time we were allotted with the review panel. And even more pleased with the very sound endorsement of our administration and corporate services in the report that followed. Congratulations to the administration and corporate managers and to all of our staff.

Robert Ginbey

Occupational health and safety

The Occupational Health and Safety (OHS) Committee provides a forum for resolving safety issues that may arise at the Institute.

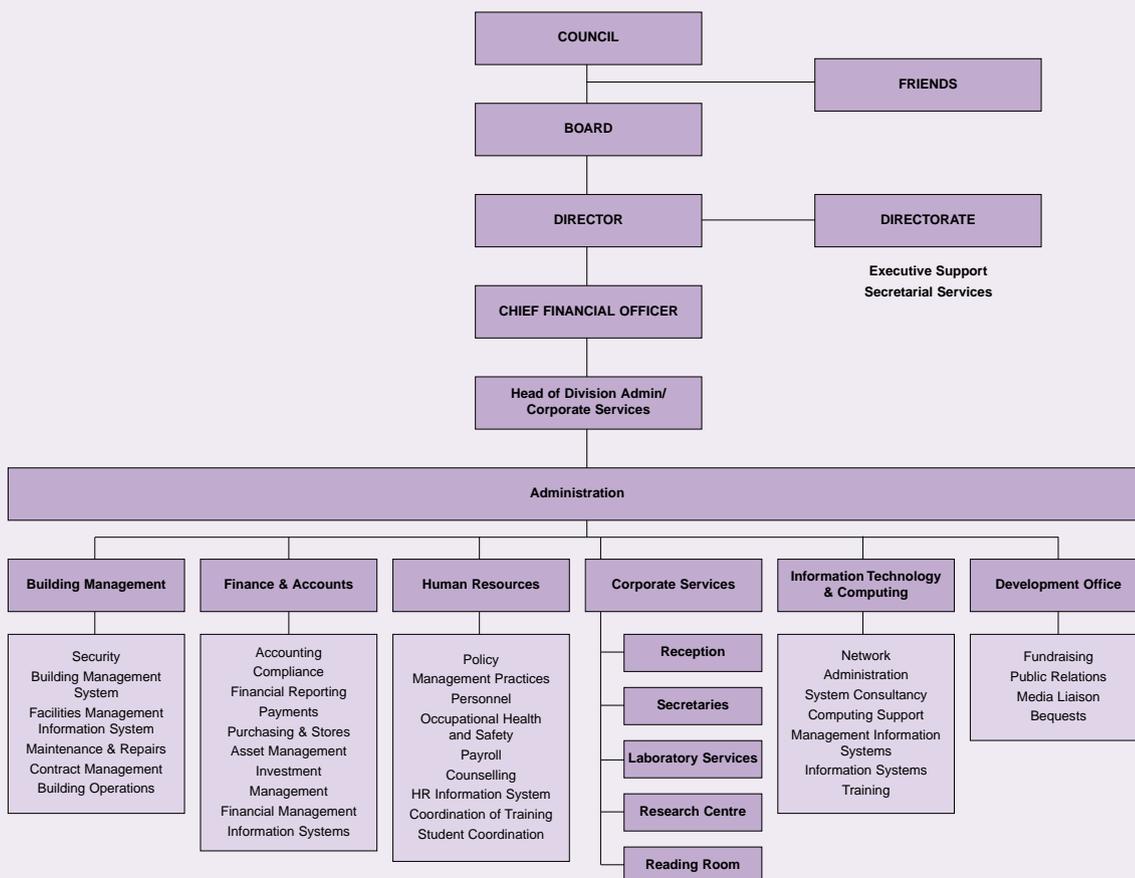
Representatives from each division meet regularly to discuss internal safety and health practices, to make recommendations to management for safety policy, to resolve problems, monitor accidents and incidents, discuss OHS training requirements and plan for emergencies.

These representatives report back to their respective divisional meetings to ensure the staff is 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.

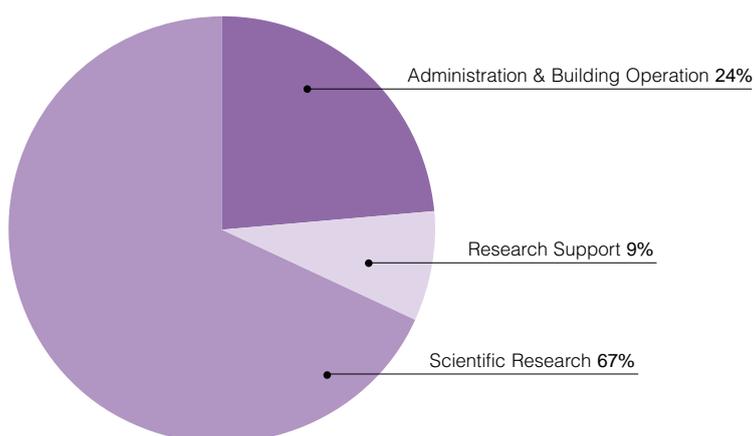
Organisational Chart Administration and Corporate Services



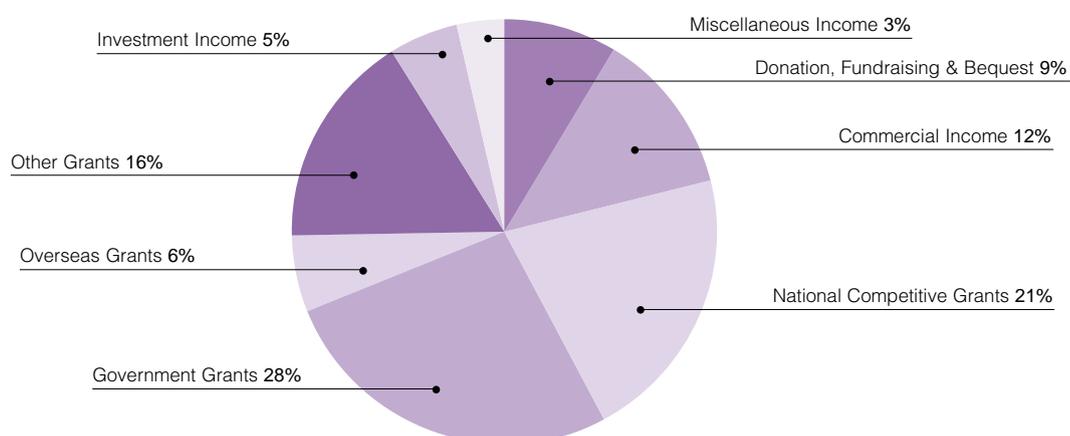
The year in brief

	2001	2000	% Change
Expenditure	14,450,465	12,297,727	17.51%
Number of Staff	226	229	-1.31%
Number of Visiting Scientists	18	24	-25.00%
Number of Postgraduates	24	28	-14.29%
Total	268	281	-4.63%

Expenditure \$14.45 million



Income \$14.09 million



Research grant income

DESCRIPTION	AMOUNT \$
Commercial Income	
GlaxoSmithKline	888,522
Aventis Pharma	16,450
Wyeth Ayerst	204,434
Abbott Australasia	44,431
Pfizer Australia	137,447
Miscellaneous – Australian commercial	122,032
ALK	68,238
Aventis-Pasteur	155,768
Miscellaneous – Overseas commercial	39,498
	1,676,820
National Competitive Grants	
NHMRC	3,455,868
Australian Rotary Health Research Fund	20,000
	3,475,868
Government Grants	
Health West (Department of Health)	1,169,784
Education Department of Western Australia	190,350
Lotteries Commission	57,242
HomesWest	71,316
Healthway	393,770
WA Drug Abuse Strategy Office	7,500
Office of Aboriginal and Torres Strait Islander Health Service	702,120
Family and Community Services	30,000
Health and Aged Care	161,414
	2,783,497
Overseas Grants	
National Institute of Health	508,002
Children's Hospital Medical Centre	33,116
Fox Chase Cancer Centre	6,600
World Health Organisation	24,357
Miscellaneous	291,890
	863,965
Other Grants	
Asthma Foundation of Western Australia	33,800
Cancer Foundation of Western Australia	53,668
Variety Club	18,560
Three Boys Legacy	7,755
Child Health Research Foundation	35,500
Children's Leukaemia Foundation	234,235
Garnet Passe	53,880
Princess Margaret Hospital for Children	310,713
Curtin University of Technology	1,000
Royal Alexander Hospital	999
Murdoch University	37,551
Kimberley Public Health	3,910
Royal Perth Hospital	50,000
Ian Potter Foundation	200,000
Western Australia Institute of Medical Research	406,920
National Australia Bank	2,273
Miscellaneous Income – Other Grants	15,365
	1,466,128
	10,266,277

Affiliated groups' reports

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. Next year marks the tenth anniversary of the Centre.

The highly successful meningococcal awareness campaign ran in collaboration with the Medical Council, Department of Health and the Amanda Young Foundation. A series of support materials were produced and distributed. The Minister for Health, Bob Kucera, launched the campaign to coincide with the peak risk season for meningitis. The campaign marked the beginning of a more collaborative approach among medical professionals.

Over 115 people made contact with the centre following our *Families, Survivors, Friends* advertisements.

We look forward to working with Wyeth Lederle Vaccines to further raise awareness of measures to prevent the bacterial forms of meningitis. Unfortunately the National Australia Bank did not renew their sponsorship.

The Management Committee are Bruce Langoulant (chair), Jag Gill (retired May), Robert Ginbey, Sarah Johnston, Michael Kailis, Tony Keil, Deborah Lehmann, Barry MacKinnon, Belinda Turner (coordinator) and Tony Watson.

Amanda Young Foundation

The Amanda Young Foundation held several very successful fundraising events during the year including the Second Annual Eco-Health Young Leaders' Summit; the Annual Rowing Fun Regatta; the second opening of Amanda's garden; and a *Night of Knights* charity ball.

The Amanda Young Foundation Management Committee are Barry MacKinnon AC (chair), Peter Dingle, Cally Hannah (from September), Bruce Langoulant, Val Mayger, Graham Rixon, Belinda Turner (coordinator), Barry Young, Lorraine Young, and Wendy Zuideveld.

Louisa Alessandri Memorial Fund

This fund perpetuates the work of a notable and much loved Institute epidemiologist. The speaker for the public oration held annually in Louisa's honour, was Dr Anne Read. Her topic was *Research is important, communication is vital - Louisa's commitment*.

The fund's annual Award for Excellence and Commitment in Research is given to a person who has contributed in an important way to the Institute. Colleen Moylan was this year's recipient. She had been with the Institute for many years as private secretary to Professor Stanley. The award was well deserved and also timely as Colleen retired in December.

This year also saw the launching of a cookbook *Good Food, Good Company* written by Louisa's mother, Phyllis Alessandri. A further important event was the announcement of a scholarship for a student with disabilities, to commence in 2002.

Friends of the Institute

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

The fundraising events of 2001 allowed the friends to assist the Institute in many ways. A postgraduate supplementary scholarship for research into birth defects; financial assistance for the Kulunga Research Network information forum; conference registration, accommodation and airfares for staff to attend interstate and international conferences; financial assistance for the Population Sciences away days; a digital camera and scanner for the Aboriginal research projects and a cancer symposium to be hosted by the Cancer Biology laboratory.

Three events were held in Perth this year: screening of the movie comedy, *Bridget Jones's Diary*; the annual ladies golf day at the Cottesloe Golf Club and the annual Christmas function. The Margaret River committee held very successful open garden days and produced a cookbook.

Friends committee members serve on a voluntary basis and bring with them a multitude of skills and experience. Committee members have changed throughout the year and we would like to thank past and current members for their support and commitment. Committee members throughout 2001 include:

Perth - Marilyn Stewart (President), Sue Bolto, Lyn Buchan, Helen Chipper, Lois Egerton Warburton, Jenny Elphick, Noela George, Tammy Gibbs, Robert Ginbey, Jackie Goldfinch, Julianne Griffiths, Vicki Haunold, Emma Lovel, Lesley Maff, Naomi Mellish, Ursula Prince, and Fiona Wildy

Margaret River - Deborah Jacob (President), Jamie Ashton, Jim Boyd, Jenni Buckingham, Aileen Budge, Pat Gray, Lynley Madson, Madeleine Miles, Helen Noakes, Jan Smith, Colleen Wilde, Chris Wilder and Rae Willis



Clear hearing: Erin Martino, 8, of Ballajura, holds the medal won by her doctor, Harvey Coates. Dr Coates was given the Fiona Stanley Medal for his dedication to paediatric ear health and research, particularly in indigenous children. Photo courtesy WA Newspapers

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 of \$4000.

This year's winner is Dr Tina Carter in recognition of her work studying critical tumor suppressor genes to gain a better understanding of acute lymphoblastic leukaemia in children.

Dr Carter presented her work at the Pasteur Institute in France and has since taken a 12 month position as a haematology/oncology clinical and research fellow at British Columbia Children's Hospital, Vancouver, Canada. In 2002 she will present her work at several important forums across the United States including the annual meeting of the American Society of Haematology.

There were many high calibre applications this year and the field was very strong. It is encouraging to see the quality and breadth of postgraduate research being undertaken at the Institute.

Donors

Hope is a precious gift. We would like to sincerely 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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In honour donations include special occasions such as a birthday, anniversary, wedding, Christmas or any occasion special to you.

In memory donations honour the deceased and their family with a lasting and worthwhile contribution to the Institute. These tributes may be in lieu of flowers.

Please send me information about tribute gifts.

Bequests

Bequests A gift for the future is a gift of healthy children generations to come. Remembering the Institute in your Will is a precious gift that we will never forget, and it will enable our vital research to continue. Planning this gift to the Institute is simple. We are happy to provide you with information on your options. We can also refer you to a solicitor, should you wish to discuss your gift further.

Please send me information about leaving a bequest to the Institute

For further information about these gifting opportunities or to discuss other opportunities, please telephone our Development Office on (08) 9489 7963 or email development@ichr.uwa.edu.au

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Please return this form to Development Office, PO Box 855, West Perth WA 6872

Gifting opportunities



Tearful memory: School friends of Caitlin Kyle gather in front of the wall built in her memory at the Institute for Child Health Research. Some of Caitlin's pictures are among those on display. Photo courtesy of WA Newspapers

“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.

Here are some ways our supporters choose to help. If you have other suggestions, we are more than willing to help you make them work.

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