



TELETHON
KIDS
INSTITUTE
Discover. Prevent. Cure.

**ANNUAL
REPORT
2013**



The Telethon Kids Institute is affiliated with The University of Western Australia through the Centre for Child Health Research and has strong clinical research links to Princess Margaret Hospital for Children.



**THE UNIVERSITY OF
WESTERN AUSTRALIA**



Government of Western Australia
Department of **Health**
Child and Adolescent Health Service

PRINCIPAL PARTNER



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KIDS are at the of everything we do



We've created a new kind of research institute – an institute where kids are at the heart of everything we do.

Our bold blueprint brings together community, researchers, practitioners, policy makers and funders, who share our vision to improve the health and wellbeing of children through excellence in research.

Over the past year, our organisation has undergone a significant transformation – reorganising our research and the structures that support it.

We're actively seeking broader collaborations and working closer with the community.

We're diversifying our funding sources with the aim of providing greater flexibility to pursue our research agenda.

And we've changed our name.

A new identity to match our new way of working. One that is bold and outgoing and embraces all who care about kids.

Together we will **Discover. Prevent. Cure.**



MESSAGE FROM THE CHAIRMAN AND DIRECTOR

When we unveiled our blueprint for a new style of research institute last year in our strategic plan, we knew that significant change was ahead.

However, the scale and pace of that change has been even greater than we first imagined.

The focus of the strategic plan was to deliver on our vision of improving the health and wellbeing of children through excellence in research. To achieve this would require a solid commitment to translating our research results into action and to involve the community, policy makers and clinicians in setting and implementing our research agenda.

Over the past year we have reorganised our research away from traditional discipline-based structures and instead set up overarching research focus areas. These areas are designed to overlap and encourage broad networks in multiple disciplines that extend well beyond the Institute. The four Research Focus Areas are Early Environment, Chronic Diseases of Childhood, Brain and Behaviour and Aboriginal Health. Our new team of Research Strategy Leaders, together with our new Research Development team, are bringing those concepts to life with the governance structure and steering committees now established. We expect that these Research Focus Areas will be the fertile ground in which new research collaborations will emerge and generate innovative new research proposals.

Funding those good ideas are the next challenge. While competitive funding grants from organisations like the National Health and Medical Research Council remain our major focus, we know that we will need to build support more broadly to achieve our research agenda. A very welcome example of this is the \$5m gift we received from Wesfarmers for four years funding to establish the Wesfarmers Centre for Vaccines and Infectious Diseases. We were also very pleased to recruit an internationally experienced Head of Development, Tim McInnis, to lead us in developing a diversified fundraising strategy.

The most visible reflection of our internal transformation is our new name and brand. After extensive research and consultation we launched the "Telethon Kids Institute" in March. The simplified name puts kids at the heart of what we do. The tagline "Discover. Prevent. Cure." clearly articulates our business. The new identity has received overwhelming support internally and externally.

Of course our name also cements our long and productive relationship with our principal partner Telethon. This extraordinary fundraiser by Channel 7 underpins so much of the work that we do and we are very proud to honour that support with naming rights into perpetuity.



The biggest opportunity and challenge on our horizon is our new facility within the Perth Children's Hospital. We are on schedule to move into the building at the end of 2015 and look forward to working in a truly collaborative environment with our clinical and university colleagues. There is no doubt that this will facilitate the translation of research from bench to bedside and help to ensure that WA children receive the very best treatment and care.

While the past year has been transformational, there is much more ahead. It has been our pleasure to welcome two new Board members to assist with this bold agenda. Kate George and Rohan Williams both bring extensive expertise and experience and we are fortunate to secure their services.

Our thanks to the Board Directors, executive, staff, students and supporters for their enthusiasm and endeavour.

A handwritten signature in black ink, appearing to read "John Langoulant".

John Langoulant, Chairman

A handwritten signature in blue ink, appearing to read "Jonathan Carapetis".

Jonathan Carapetis, Director



BOARD OF DIRECTORS

Our Board of Directors all give their time voluntarily and work together to guide the overall business of the Institute, bringing a diverse range of experience from the business, academic and community sectors. We are extremely grateful for their dedication and the governance they provide us.

JOHN LANGOULANT AO (CHAIR)



Former Chief Executive, Oakajee Port and Rail and Crosslands Resources Pty Ltd; Chair of the Board, Western Australian Ballet; Chair of the Board, Committee for Perth; Board Member, Council of Australian Governments (COAG) Reform Council; Chairman, Leadership WA; Chairman, Government Employees Superannuation Board; Chairman, Dampier to Bunbury Pipeline; Member of the Board, CCIWA; Chairman, Western Australia Westpac Bank.

JONATHAN CARAPETIS



Director, Telethon Kids Institute; Member, Western Australian Immunisation Strategy Implementation Steering Committee; Chair, Clinical Advisory Group, WA RHD Control Program State Health Research Advisory Council; Member, One Disease at a Time Board; Member, Program Management Committee, RHD Australia; Member, National Committee for Medicine, Australian Academy of Science.

JEFF DOWLING



Former Managing Partner, Ernst & Young Western Region; Fellow, Australian Institute of Company Directors; Fellow, Institute of Chartered Accountants Australia; Fellow, Financial Services Institute of Australasia; Board Member, West Australian Symphony Orchestra; Director, Atlas Iron Limited; Deputy Chair, WA Metropolitan Redevelopment Authority; Chairman, Sirius Resources NL; Non-Executive, NRW Holdings Ltd; Chairman, Pura Vida Energy Limited.

KATE GEORGE



CEO Kariyarra Mugarinya Development; Director and Principal Consultant, Claypan Services Pty Ltd; Member of Pilyparra Ngurrara Working Group.

ANNE KELSO AO



Director, World Health Organization Collaborating Centre for Reference and Research on Influenza; Honorary Professorial Fellow, The University of Melbourne; Member, Council of the National Health and Medical Research Council; Member of Board of Trustees, International Society for Influenza and other Respiratory Diseases; Board Member, Florey Institute of Neuroscience and Mental Health.

MICHAEL MANFORD



Executive Chairman, Patersons Securities Limited; Chairman, Patersons Asset Management; ASIC Market Disciplinary Panel Member; Councillor, St Hilda's Anglican School for Girls.

MICHAEL McANEARNEY



Director, CEO & Co-Founder, Gerard Daniels; Member, Australian Institute of Company Directors; Director, Duke of Edinburgh Award WA.

JIM MCGINTY AM



MLA Chairman, Health Workforce Australia; Board Member, Australian Medicare Local Alliance and Fremantle Medicare Local; Former WA State Health Minister; Former WA Attorney General.

ROBYN OWENS



Deputy Vice-Chancellor (Research), The University of Western Australia; Member, Australian Astronomical Observatory Advisory Committee; Member, Centre for Ethical Leadership Advisory Board; Member, International Centre for Radio Astronomy Research Board; Member, National eResearch Collaboration Tools and Resources Project Board; Alternate Board Member, Harry Perkins Institute of Medical Research; Board Member, Astronomy Australia Limited; Member, EMBL-Australia Council; Member, Scotch College Board.

ROHAN WILLIAMS



Executive Chairman, Dacian Gold Limited; Former CEO and Managing Director, Avoca Resources Ltd; Non-Executive Director, Alacer Gold Corp.



2013 HIGHLIGHTS

The Telethon Kids Institute continues to conduct high quality research to improve the health and wellbeing of all children. In 2013, our researchers were nationally and internationally recognised for their unwavering commitment to multidisciplinary research, their forward-thinking research programs, and their ongoing advocacy for the health and wellbeing of children. The year also saw the Telethon Kids Institute partner with numerous international research leaders and institutions on pioneering research initiatives.

WELCOME DONNA

Internationally recognised child health researcher Professor Donna Cross and her team joined the Telethon Kids Institute. Professor Cross has an international profile in school health promotion intervention research and is a renowned campaigner for the wellbeing of children and young people.



CENTRE OF EXCELLENCE

Our researchers will play a significant role in a new multi-million dollar Centre of Excellence aimed at investigating – and breaking – the generational cycle of social disadvantage. Telethon Kids Professors Stephen Zubrick and David Lawrence will play a key role in the \$24M ARC Centre of Excellence for Children and Families over the Life Course.

VITAMIN D AND DEPRESSION

Our research has shown that low vitamin D levels are associated with increased symptoms of depression in males. This research supports previous studies that identified the link between vitamin D levels and brain activity. Vitamin D appears to be involved in brain function and it is thought to help to control symptoms of depression by altering chemical balances.

KIDS MENTAL HEALTH

During 2013, we started the Young Minds Matter survey, the second national survey to look at the mental health and wellbeing of Australian children. More than 6000 Australian families were randomly selected to take part in the study which will be instrumental in shining new light on how the kids of today are coping with new challenges and new pressures in a changing world.

COMMITMENT TO ABORIGINAL CHILDREN AND FAMILIES

In November we launched our Commitment to Aboriginal Children and Families 2013-2017. The Commitment outlines the guiding principles for our work in Aboriginal child health and the priorities to be addressed. We have a proud history of research and advocacy with Aboriginal families and we now seek to draw upon this, and further build partnerships with the community and stakeholders, to address the big issues faced by Aboriginal kids.

LEUKAEMIA RESEARCH

A study by Institute researchers examining drug resistance in leukaemia patients shed new light on why some treatments may be more effective than others.

The study looked at cells from children suffering from T-cell acute lymphoblastic leukaemia and examined how different genes were associated with resistance to different drugs in an effort to improve treatment success.

The results were used to identify genetic fingerprints that indicate which cancer cells may be more drug resistant than others. The team then examined these patterns in patients from larger international studies and were able to confirm the accuracy of the findings.

AWARDS

Dr Hannah Moore and Associate Professor Graham Zosky were awarded the prestigious 2013 Young Tall Poppy Science Awards.

The 2013 Dr Bob Elphick Medal for outstanding contributions to tobacco control was awarded to Dr Juli Coffin from the Institute's Centre for Research Excellence in Aboriginal Health and Wellbeing and Research Coordinator at Geraldton Regional Aboriginal Medical Services. The award is presented by ACOSH, the Australian Council on Smoking and Health. Juli is pictured below receiving the award from Professor Bryant Stokes.





APP FOR AUTISM

The Telethon Kids is assessing the effectiveness of an innovative iPad App to see if it improves outcomes for kids with autism.

The study is the first in the world to document the effectiveness of an educational App for children with autism. It will also evaluate whether the App empowers parents to feel a sense of control over their child's therapy.

If effective for kids with autism, it could substantially ease the financial burden on families while ensuring children receive therapy.

GLOBAL SYMPOSIUM ON CHILDHOOD BRAIN TUMOURS

Over three days in February, more than 50 international brain tumour experts discussed better ways to tackle the most common and highly invasive form of childhood brain tumours, Medulloblastoma, which affects one in five children who have a brain tumour.

Funded by the Telethon Adventurers and supported by the Telethon Kids Institute, Medulloblastoma Down Under 2013 aimed to identify better ways of sharing knowledge about the biology of the disease, improved targeting of drug therapies and the development of new strategies to push past the limits that have already been reached by current day radiation and chemotherapy treatments.

The final report from the meeting was published

in the prestigious journal *Acta Neuropathologica* in September.

ENERGY DRINKS

We published research showing that energy drink consumption is significantly associated with anxiety in males.

Researchers say they don't know exactly why the link exists between anxiety and energy drink consumption, but there is some belief it could relate to the high levels of caffeine in these drinks and the association between caffeine and detrimental mental health effects such as anxiety disorder and panic disorder.

NEW STUDY TO TRACK DEVELOPMENT IN THE MIDDLE CHILDHOOD YEARS

Researchers from the Telethon Kids Institute were awarded an ARC Linkage Grant to develop a new measure of how well Australian children are doing during middle childhood.

The grant will be used by to develop a Middle Development Instrument in collaboration with UWA, Menzies School of Health Research, The University of British Columbia, South Australia Department for Education and Child Development and WA Department of Education.

GASTROENTERITIS

The Telethon Kids conducted the world's largest study of gastroenteritis trends in children which showed the gap between Aboriginal and non-Aboriginal health may be improving. The study results showed that between the periods 1983-1994 and 1995-2006 the hospitalisation rate for gastroenteritis dropped significantly in young Aboriginal children.

Several possible reasons for the drop include a decline in the severity of the diseases and general improvement in Aboriginal health and hygiene.

Further research is need to document the impact of the introduction of the rotavirus vaccine in 2007.

ADHD RESEARCH

One of the largest population studies of Attention Deficit/Hyperactivity Disorder (ADHD) in children has revealed maternal smoking during pregnancy to be an important risk factor.

The study of 12,991 WA children diagnosed with ADHD found that, compared with mothers whose children did not have ADHD, mothers of children with ADHD were significantly more likely to be younger, single, smoked in pregnancy, had some complications of pregnancy and labour and were more likely to have given birth slightly earlier.

Lead author Dr Desiree Silva cautioned that the study had identified broad risk factors rather than causes and that the information could not be used to identify the factors associated with any particular child's disorder.

LANGUAGE DEVELOPMENT

A world-first study by Telethon Kids has identified risk factors for receptive language development in Australian children.

Receptive language is the ability to derive meaning from words and builds the foundation for language acquisition and literacy. Low receptive language ability is a risk factor for under-achievement at school.

The study found a range of factors were associated with receptive language delay at four years of age including the mother being from a Non-English Speaking Background (NESB), low school readiness, child not read to at home and the child having four or more siblings.

However, none of these risks were associated with a lower rate of growth in the child's language from four to eight years.

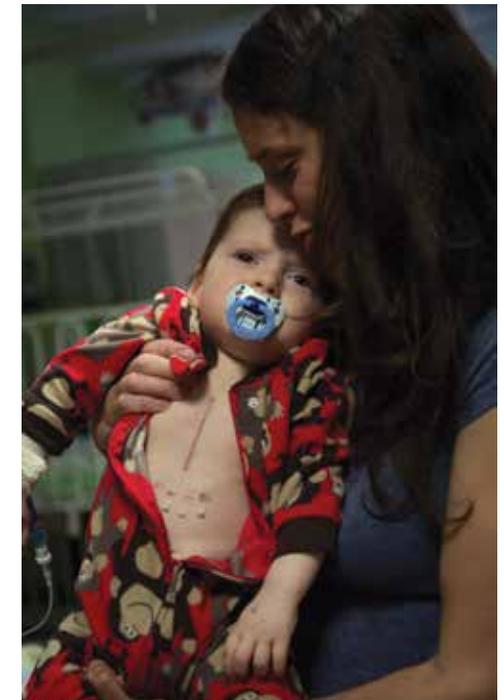
WESFARMERS CENTRE OF VACCINES AND INFECTIOUS DISEASE

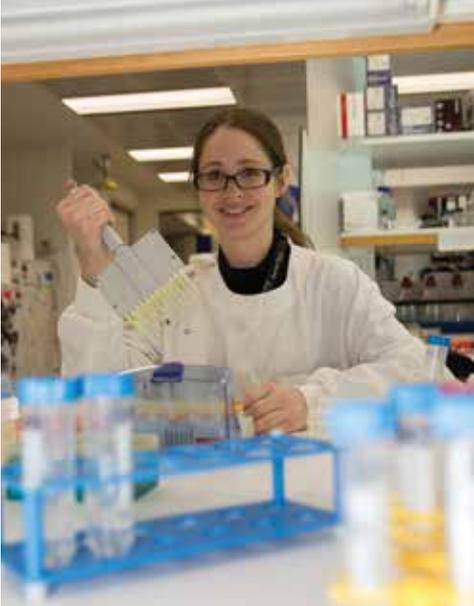
Wesfarmers donated \$5 million over four years to establish the Wesfarmers Centre of Vaccines and Infectious Diseases at the Telethon Kids Institute.

The Wesfarmers Centre will be a game changer in its field, bringing together researchers and clinicians at the Telethon Institute, PMH and WA's universities to deliver new vaccines, diagnostic tests and devices.

The Wesfarmers Centre will initially work on streptococcal infections, rheumatic heart disease, pneumonia, influenza, gastroenteritis and serious bloodstream infection which collectively account for around 2,000 children being admitted to hospital in WA each year.

The Wesfarmers Centre will help kids like Gordy (below) who in 2013 had an infection with the staphylococcus bacteria surrounding his heart.





VITAMIN D AND LUNGS

Our research has shown a connection between vitamin D deficiency and bacterial infections in the lungs that could bring on, or exacerbate, asthma attacks.

The study also showed that boys with low vitamin D levels are potentially more susceptible to the onset of asthma from lung bacteria than girls.

Lead Author Dr Shelley Gorman (pictured above) said the study re-enforced the key role good vitamin D levels play in keeping our kids healthy.

CYSTIC FIBROSIS

Our researchers studied 127 infants diagnosed with cystic fibrosis (CF) and reported that they could determine which children were at most risk of developing bronchiectasis by three years of age.

The study shows children with CF who have neutrophil elastase in their lungs at three months are seven times more likely to develop bronchiectasis by 12 months, and four times more likely by three years. Neutrophil elastase

is one of the body's mechanisms for destroying bacteria in the body.

The levels of neutrophil elastase in the body is normally controlled, however in CF excess neutrophil elastase can cause breakdown of the lung structure. This leads to irreversible lung damage like bronchiectasis.

If a mechanism for mopping up neutrophil elastase can be developed then damage to the lungs can be delayed or prevented.

MALE FERTILITY

Results from our Western Australian Pregnancy Cohort (Raine) Study showed that male babies that do not have good fetal growth or are exposed to their mothers' smoking are more likely to have a lower sperm count as adults.

EAR INFECTIONS

New findings could reduce the need for antibiotics and surgery for kids with middle-ear infections, and help tackle hearing loss in Indigenous communities.

The Institute's Dr Ruth Thornton (pictured right) is part of the team that has discovered that sticky nets of DNA hide bacteria in the ears of kids with recurrent middle-ear infections, and evade antibiotic treatment by creating impenetrable slimy biofilms.

The researchers are targeting these nets with a drug that has already proven its ability to help kids with cystic fibrosis by breaking up thick secretions in their lungs. Clinical drug trials are now underway.

SUGAR INTAKE MONITORING

A new study has ignited calls for better collection of data on food sugar levels as part of the ongoing battle against rising obesity after researchers analysed data relating to sugar supply and consumption over a 22 year period (1988-2010).

The study also raised concerns over the increasing level of imported processed foods being consumed by Australians, and the high sugar content they contain.

The analysis showed a large increase in the volume and value of imported sweetened products into Australia suggesting that per capita, sugar consumption has been increasing since 1988 and this may well be having an impact on the dietary health of our nation.

NATIONAL AUTISM RESEARCH

The Telethon Kids Institute will play a key role in a ground breaking, multi-million dollar Cooperative Research Centre for Living with Autism Spectrum Disorders. The Centre will bring together the most respected autism

researchers and scientists from across Australia, including a Telethon Institute team led by Professor Andrew Whitehouse.

The new national research centre is a game-changer in the ongoing fight to better understand the causes of autism and offer new hope to the families impacted by it.

CONSUMER AND COMMUNITY PARTICIPATION IN RESEARCH

During 2013, highlights of our program in consumer and community participation included:

- 92 consumers on 11 committees and reference groups at the Institute
- 100 participants attended training at the Institute, UWA and in South Australia and Victoria
- 7 "community conversation" events were held for the Institute on education research, the new building and the strategic plan
- Members of our team gave three national and four international presentations.





CARDIOVASCULAR DISEASE

Teenagers who drink more than one standard can (375g) of sugary drinks a day are putting themselves at higher risk of developing Type 2 diabetes and cardiovascular disease, such as heart disease or stroke, later in their lives.

Our study found that teenagers who drank about a can of soft drink a day had lower levels of 'good' cholesterol and higher levels of the 'bad' triglyceride form of fat in their blood, regardless of whether they were overweight.

Based on a combination of factors associated with Type 2 diabetes and cardiovascular disease, including weight, blood pressure and cholesterol

levels, these teenagers were at higher risk of developing cardiometabolic disease later in life.

MENTAL HEALTH

The gap between life expectancy in patients with a mental illness and the general population has widened since 1985 and efforts to reduce this gap should focus on improving physical health, our research suggests.

The higher death rate associated with mental illness has been extensively documented, but most of the attention has focused on the elevated risk of suicide, whereas most of the risk can be attributed to physical illness such as cardiovascular and respiratory diseases and cancer (80% of deaths).

Our study demonstrates a widening gap in life expectancy of 16 years for males and 12 years for females: the overall gap has increased by 2.4 years for males and 1.6 years for females since 1985.

BRAIN TUMOURS

Parents exposed to professional pesticide treatments prior to conception could increase the chances of a child developing a brain tumour.

Our researchers examined professional pesticide exposure in the year before pregnancy, during pregnancy and after the child is born, revealing a link between the timing of the exposure and the type of pesticides involved.

Of the pesticide treatments reviewed it appeared that professional termite treatments posed a greater risk than other general insecticide treatments. The increased risk associated with termite treatments may be as high as two-fold, while the increased risk with other pesticides may be about 30%.

Researchers cautioned that the results did not mean that pesticide exposure had caused brain tumours in children in the study as there are likely to be many causes of childhood brain tumours.

DIET/NUTRITION

New results from the Telethon Kids indicate a Western style of diet is associated with an increased risk of non-alcoholic fatty liver disease at 17 years of age and a healthy diet was protective, particularly in obese adolescents.

A "Western" diet is characterised by a high intake of takeaway foods, red meat, confectionary, soft drinks, processed, fried and refined foods.

These diets tend to be higher in total fat, saturated fat, refined sugar and sodium. A "healthy" pattern is a diet high in fresh fruit and vegetables, whole grains, legumes and fish. It tends to be higher in omega-3 fatty acids, folate and fibre.

INTELLECTUAL DISABILITIES

Children with an intellectual disability or autism are up to ten times more likely to be admitted to hospital than unaffected children.

The research team looked at more than one million hospital admission records from 416,611 WA children born between 1983 and 1999. Children with an intellectual disability or autism were placed into one of five categories and compared with the remainder of the children.

The study also showed that compared to unaffected children, those with a known medical cause for the intellectual disability (such as Down or Rett syndrome) were more than seven times more likely to be hospitalised and those with mild/moderate intellectual disability (children with an IQ of 40-70 where the cause is unknown) were three times more likely to require hospital admission.

FASD

A study of the Western Australian justice system has identified that up to 85 per cent of staff say responding to the needs of people with Fetal Alcohol Spectrum Disorders (FASD) is an issue in their work.

The report by the Telethon Kids Institute recommends greater awareness, better training and education and alternate sentencing options that consider the neurocognitive impairments associated with FASD.

FASD results from fetal exposure to alcohol. It is an umbrella term used to describe a range of cognitive, physical, mental behavioural, learning and developmental disorders.

For more information about our research, visit telethonkids.org.au



During 2013 we supported
105 Honours, Masters and PhD students
with completions including:
12 PhDs **9** Honours **1** Masters



OUR SUPPORTERS

We are honoured by the philanthropic support our work receives and are grateful to each of our donors. Every gift we receive is an expression of the hope and trust our donors have in us to discover cures and new preventive health solutions for children.

Thank you to all of our donors and supporters. We highlight a few examples of how our donors are supporting our Research Focus Areas as well as our research platform.

Thanks Telethon

Channel 7 Telethon is the Institute's Principal Partner and the largest single donor to child health research in the State. The Telethon Kids Institute has been a major beneficiary since the very beginning of Telethon and without their support and the support of the thousands of Western Australians who give to Telethon, we would not be able to do the vital research that we do.

Thank you Telethon and thank you Western Australia for your incredible support.



Stan Perron Charitable Foundation

Stan and Jean Perron and their Foundation have been supporting the Institute since its establishment and for this we are truly grateful.

Last year, Stan and Jean supported five scholarships at the Institute allowing researchers to focus primarily on completing their research, without the pressure of applying to other funding sources or obtaining additional employment.

Thank you Stan and Jean.



PHOTOS COURTESY VIVA LIFE PHOTOGRAPHY



RESEARCH FOCUS AREA: EARLY ENVIRONMENT

The early environment affects health and development in childhood and beyond.

Its influence starts from before a child is even conceived - that's why we also need to care about the health and wellbeing of prospective parents.

Factors including infection, climate, nutrition and physical activity, sunlight, the built environment, pollutants and the complex range of bacteria living in and around us, all can have an impact.

Understanding these exposures and their impact on children, particularly in early life, is key to preventing and treating a number of common, chronic conditions in childhood and beyond.

Thanks to those donors supporting our Early Environment research.

WESFARMERS

Thank you to the Wesfarmers Board and Executive for the company's very generous gift of \$5 million over 4 years to establish the Wesfarmers Centre of Vaccines and Infectious Diseases.

Our renewed partnership builds upon almost two decades of Wesfarmers and the Telethon Kids Institute working together to improve the health and wellbeing of children.

This new Centre is a game-changer in infectious disease research. The outcomes from this research will be significant in improving child health, particularly for Aboriginal children and disadvantaged populations around the world.



Wesfarmers

ALLEGRA SCAFIDAS FUND

Parents Elias Scafidas and Nhon Vo have established the Allegra Scafidas Fund, in honour of their daughter Allegra who died in 2010 at just six months of age from pneumococcal meningitis.

The Fund was established to support the advancement of pioneering knowledge and research into the prevention of pneumococcal disease. With support from the Fund, the Telethon Kids Institute has set up a specialised laboratory, the Allegra Scafidas Pneumococcal Laboratory, for research to better understand the causes, diagnosis, treatment and prevention of pneumococcal disease.

A prestigious award is also presented annually to recognise innovative research with a special focus on infectious diseases and vaccination.



NHON VO AND ELIAS SCAFIDAS WITH
AWARD RECIPIENTS RUTH THORNTON
AND ANGELA FUERY



IMOGEN'S MOTHER JENNY SULESKI
AND GRANDMOTHER JAN LORD



IMOGEN MIRANDA SULESKI FELLOWSHIP

Baby Imogen Miranda Suleski was born premature and lost her life just a few hours later. The Fellowship in her name will support outstanding early career researchers at the Telethon Kids Institute to undertake research into risk and protective factors before and during pregnancy, around delivery and in early infancy to improve outcomes for babies.



RESEARCH FOCUS AREA: BRAIN AND BEHAVIOUR

Brain and behaviour is at the core of many issues affecting the ongoing health and wellbeing of kids.

At the Telethon Kids Institute, this research encompasses a child's learning, development and mental health - and the impact of conditions like cerebral palsy, autism and intellectual disability.

Our research investigates the developmental, genetic, family and environmental determinants of child wellbeing, and how clinical, educational and community practices can provide every child with the best opportunity for optimal health and development.

HAWAIIAN AND FARMER JACKS SUPERMARKETS

Thank you to Hawaiian and Farmer Jacks Supermarkets for attending our 'An Evening for the Future of Autism' event in March 2013.

We received very generous gifts from Hawaiian and Farmer Jacks Supermarkets which go towards our autism research which is looking at causes, new interventions and improved therapies for kids with autism.



RESEARCH FOCUS AREA: CHRONIC DISEASES

Chronic diseases in children require very different investigation and treatment to similar conditions in adults.

Childhood cancers, diabetes, lung and heart diseases are debilitating and often life threatening.

Effective treatment and prevention requires a comprehensive understanding of the interactions between genetic and environmental factors.

Our focus is on better ways of diagnosing, treating and controlling disease in individual kids as well as reducing these diseases in the population as a whole.

Our thanks to those donors supporting our Chronic Diseases research.

LAURENCE CHEUNG
RECEIVES HIS SCHOLARSHIP
AWARD FROM THE
FOUNDATION'S PHIL BRUCE

CHILDREN'S LEUKAEMIA AND CANCER RESEARCH FOUNDATION

Since 1979 the Children's Leukaemia and Cancer Research Foundation has raised 21 million dollars for childhood cancer research.

Their support of our work in childhood leukaemia and cancer research has underpinned our research from the very beginnings of this Institute.

One of the many ways they support our work is through several Fellowships and Scholarships. Currently they are funding nine Telethon Kids researchers and we are indebted to Chairman Geoff Cattach and his team at the Foundation for all of their support.



TELETHON ADVENTURERS

The Telethon Adventurers continued their war on childhood cancer in 2013 raising over \$1.6 million.

The group's dedicated fundraising community continued its crusade all over the world; climbing mountains in Bolivia and Italy, cycling in Europe and the South West, trekking Kokoda, running a marathon in the Antarctic and skydiving over the shores of WA - all in the name of adventure and raising money for childhood cancer research.

In February 2013, the Adventurers hosted 50 of the world's leading neurosurgeons, researchers and oncologists here in WA to identify better ways of sharing knowledge, improving drug therapies and to develop research strategies for the future.

To conclude the year, Founders Rick Parish and Peter Wilson opened the Telethon Adventurers Brain Tumour Laboratory here at the Telethon Kids Institute.



THE 2013 TELETHON ADVENTURERS
CHAMONIX CHALLENGE

BRIGHT BLUE THE POLICE COMMISSIONER'S FUND FOR SICK KIDS

Thanks to the generous support of Bright Blue we have been able to complete the Bright Blue Cancer Analysis Suite. This Suite assists our research team in finding ways to prevent and treat cancer in children.

This central suite for tissue processing, embedding and staining means all stages of the process can be performed onsite at the Telethon Kids Institute. Using current and proposed new instruments, such as those linked with the Bright Blue 3D Confocal Microscope, we can speed up and streamline our research capability, permitting the efficient and timely processing of tumour tissue.

This facility not only benefits childhood cancer research but also greatly benefits other groups in the Institute whose members research additional aspects of child health including respiratory diseases such as asthma and cystic fibrosis, infectious diseases and drug development.



THE BRADY CANCER SUPPORT FOUNDATION

Thanks to the Brady Cancer Support Foundation, the project “Therapy for Infant Leukaemia” is making great progress. Their ongoing support over the last 3 years has been instrumental in enabling researcher Jette Ford, Professor Ursula Kees and her team to screen hundreds of compounds to search for combinations of drugs that are effective in infant leukaemia.

Jette has proven a master at growing these cells in the laboratory, and we have developed exciting new drug sensitivity data to help improve therapy for patients.

MEDTRONIC AUSTRALASIA PTY LTD

Medtronic very generously supports our diabetes research. Their gift in 2013 has supported educational opportunities for our researchers in various areas including important courses and materials.

ETHAN DAVIES SCHOLARSHIP FOR BRAIN CANCER RESEARCH

In January 2012, at the age of just 20 months, little Ethan was diagnosed with ependymoma, an aggressive form of childhood brain cancer.

Ethan has endured several surgeries, chemotherapy and radiation therapy. He has had to learn to sit, crawl, walk and eat a second time over and he faces long-term developmental side effects from his treatment.



Although faced with the hardships of Ethan’s illness and recovery, Shannon and Christie-Lee Davies established the Ethan Davies Scholarship for Brain Cancer Research.

Ethan’s Scholarship supports trainee neurosurgeon, Dr Sasha Rogers, in the Telethon Kids Institute’s brain cancer laboratory, with a particular focus on ependymoma.

We are truly grateful for their support.



RESEARCH FOCUS AREA: ABORIGINAL HEALTH

The need to improve the health and wellbeing of Aboriginal children and families is a priority in every research focus area at the Telethon Kids Institute.

There are, however, specific cultural, social and economic contexts that require more specialised investigation in collaboration and consultation with Aboriginal families - and there are health issues that disproportionately affect Aboriginal people.

This collaborative way of working will also provide models that can be applied to other vulnerable populations in Australia and globally.



McCUSKER CHARITABLE FOUNDATION

Thank you to the McCusker Charitable Foundation for their generous support of The Marulu FASD Strategy.

The support of the Foundation has enabled us to employ Dr James Fitzpatrick in the role of Marulu Strategy Director.

The Marulu FASD strategy is a multi-pronged strategy including prevention, diagnosis, therapy, advocacy and translation with the overall goal to Make FASD History in the Fitzroy Valley.

CAGES FOUNDATION

Thank you to the CAGES Foundation (founded by the Sydney-based Salteri family) whose support has established the Marulu School Clinics in the Fitzroy Valley.

The CAGES funding has supported a full time psychologist, based in Fitzroy Crossing since 2012, to coordinate multidisciplinary clinics with existing health service providers and in partnership with Nindilingarri Cultural Health Services and Patches Paediatrics.

This model brings together allied health, paediatric and nursing staff, with teachers and families to provide a holistic diagnostic and treatment process for children with complex medical and developmental issues.

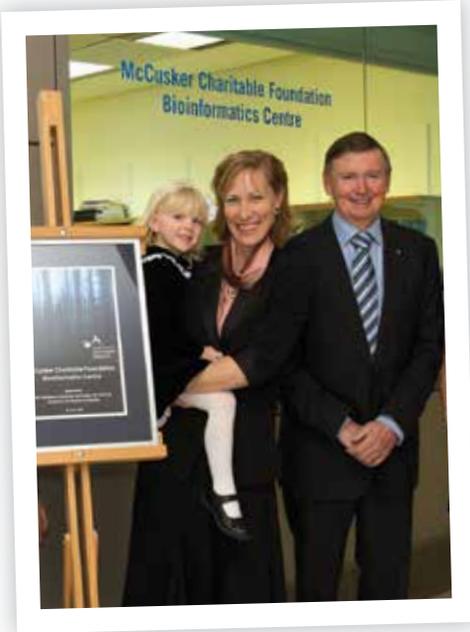


RESEARCH PLATFORM

The Telethon Kids Institute has a range of specialised expertise and technology to undertake cutting-edge science.

These tools and platforms enable our Research Focus Areas to collect, link and analyse samples and data sets to create new knowledge in the underlying mechanisms and risk factors leading to childhood disease, disability and disadvantage.

Our thanks to the donors supporting our Research Platform.



McCUSKER CHARITABLE FOUNDATION

We gratefully recognise the McCusker Charitable Foundation's ongoing support for the Telethon Kids Bioinformatics Centre, specifically, for funding our team of bioinformaticians. Bioinformatics processes and analyses billions upon billions of pieces of genetic information to support multiple research units at the Institute.

MITSUBISHI DEVELOPMENT

Mitsubishi Development has supported the Mitsubishi Clinical Suite over the last 3 years. Their funding of the clinical suite provides facilities for researchers to meet with children and families participating in studies and trials in areas including autism, vaccine trials and language development.

QANTAS

We are grateful to Qantas for supporting the national and international travel of our researchers to further their collaboration with other leading-edge scientists in child health.

GERARD DANIELS

Our thanks to Gerard Daniels for their assistance with strategic recruitment of key research and professional leadership staff.

HIS EXCELLENCY AND MRS McCUSKER WITH THEIR DAUGHTER MARY AT THE LAUNCH OF THE McCUSKER CHARITABLE FOUNDATION BIOINFORMATICS CENTRE

ST GEORGES DAY COMMITTEE

Over the past decade, the St Georges Day Committee donated an amazing \$215,700 to support research at Telethon Kids. The money was raised through balls and lunches organised by a committee led by Ken Mesure, Andrew Norris and Paul Chapman.

KPMG

Thank you to KPMG for generously giving auditing services to the Institute every year.

ACQUIRE TECHNOLOGY SOLUTIONS

acquire Technology Solutions has supported the Institute for the past 10 years as a loyal and valued partner. Their support includes philanthropic donations and practical support.

MAUREEN SQUIRE

Maureen has been giving generously to the Institute for the past four years in memory of her brother who passed away in 2010.

CSG

A big thank you to CSG, our laser printer provider, who gave a generous corporate gift last year to support our child health research.

BENZ INDUSTRIES

Bob Bollen and Benz Industries have been generously giving to us for the last six years. We thank them for their ongoing support to child health research.

ALLENS

Allens' generous pro bono legal advice has been invaluable in implementing our People Strategy including their high-quality employee relations advice and support.

SERCO

Thanks to Serco for supporting a scholarship for an Honours student in bioinformatics.

SMARTLINE PERSONAL MORTGAGE ADVISERS

Thank you to Smartline Personal Mortgage Advisers for their generous gift in support of the Institute's overall research strategy.





“Somewhere, something incredible is waiting to be known.”

Dr Carl Sagan, scientist



WORKING TOGETHER - IMPLEMENTING THE STRATEGIC PLAN

The implementation of our strategic plan requires the transformation of key elements of the Institute.

This has been most visibly reflected in the changes to the organisational structure, the appointment of Research Strategy Leaders, the identification of our Research Focus Areas and the development of our new identity as Telethon Kids Institute.

And there's much more ahead. These developments will enable the organisation to better support its people to do the highest quality research and translate that knowledge into real improvements in child health and wellbeing.

The business plans to deliver on the strategic goals are being developed under five key areas:

OUR RESEARCH STRATEGY

At its heart are the Research Focus Areas -- collaborative networks that will also include external researchers, health services and consumers to ensure our research is translated into real outcomes for children.

The four Research Focus Areas have been identified as:

- Early Environment
- Chronic Diseases of Childhood
- Brain and Behaviour
- Aboriginal Child Health.

Six initial showcase projects have been identified as exemplars of our commitment to collaboration and translation. Read more about them on pg 18.

OUR BRAND STRATEGY

Our brand is the underpinning platform for collaborators, funders and future and current employees to come together with a shared purpose and work to improve the health and wellbeing of children. It helps us to tell our story and to connect with others. The brand review identified four key pillars:

- Visibility
- Tangibility
- Collaboration
- Credibility.

Read more about how our new identity helps to bring our strategic plan to life on page 16.





OUR PEOPLE STRATEGY

Our people strategy will enable the development of a high performing culture with clear expectations and accountability that link reward and recognition to performance. The new Career Management Model will ensure our sustainability through the recognition and management of talent and will empower our people to have greater visibility and support throughout their career.

The People Strategy is reliant on the creation of People Units to ensure that:

- An individual’s career is supported by someone in addition to their day-to-day supervisor
- There are clear communication channels to allow for greater collaboration and dissemination of information – both up and down
- Professional learning and development is supported.

These People Units will include all staff and full time students and be led by a People Leader who will facilitate the performance development review process and ensure employees are supported in their career.

OUR TECHNOLOGY STRATEGY

Technology is a key enabler for any organisation, and is particularly important for the Institute due to the frequent use of large data sets, need for automated record keeping and collaborations that extend beyond the organisation.

There are two key initiatives underway:

- Information Management Project

This project will provide the tools and processes required for our staff to better share and manage knowledge, collaborate and increase productivity. The initial scoping phase is complete and a road map is now being developed for implementation that considers short term organisational priorities (collaboration tools), medium term constraints (paper lite requirements of the new building) and longer term strategic investments.

- Big Data/Bioinformatics capacity

Building high level informatics (big data) capability is a core business driver for the future of the Institute and medical research. To date the McCusker Charitable Foundation Bioinformatics Centre has been established, and a Bioinformatics Manager appointed. An Academic Head of Computational Biology has been recruited to drive the Institute’s research agenda in this capacity.

OUR VALUE CHAIN STRATEGY

The provision of world class research support services will enable our researchers to conduct high quality research and attract research talent and funders alike. A project to ensure that our value chain is cost optimised with clear performance expectations and a focus on customer service is underway.

New initiatives include:

- A Clinical Research Support Office is being developed to improve governance and practices across the Institute and wider campus
- A Risk and Business Continuity Framework.

Future priorities include research platform development and procurement processes.

You can download a copy of our Strategic Plan at telethonkids.org.au

STRATEGIC GOALS

1 Our research will be driven by its potential to improve health and wellbeing of children

2 We will work together with stakeholders to achieve the best health and wellbeing outcomes for children

3 We will build capacity and excellence in our people, in recognition that they are our greatest asset

4 We will be a great organisation in the eyes of our staff, supporters and other stakeholders

5 We will diversify and increase our funding base to sustain our activities and future growth



WHAT'S IN A NAME?

For more than 20 years our Institute has worked and advocated for children and families in Western Australia and nationally.

We've had some great successes and a great champion in our Founding Director Professor Fiona Stanley.

However, when we did some market research it became clear that while many knew something about us, many also confused us with other organisations and surprisingly few knew our name.

While that's not unusual for many similar organisations, for us it was a significant issue.

How could we fulfil our strategic goals of translating our research into action and involving the community unless we had a robust identity of our own?

After a competitive tender process, the Institute appointed leading Perth agency 303Lowe to undertake the brand project.

They consulted internally, with external stakeholders and the community more broadly.

The message was clear. When people found out who we were and what we did, they wanted to know more.

There was genuine interest in hearing our story and becoming involved.

To achieve that, we needed a short sharp name that could be remembered. We also needed a more engaging visual identity that would stand out in a crowd.

And, there was overwhelming support for Telethon – people loved and trusted our

connection with Channel 7's iconic fundraiser.

So the search for the new name began. We considered 86 names, 33 taglines and then 22 visual interpretations.

In the end we landed somewhere quite simple: **Telethon Kids Institute.**

And the tagline tells the story: **Discover. Prevent. Cure.**

The new identity was officially launched in March 2014 with a community celebration.

It's a key part of the implementation of our strategic plan in connecting people, internally and externally, to our organisation.

Plans are now underway for a substantial marketing campaign to promote the Institute and encourage people to become involved in our

activities – to inform our research, to implement our research, to participate in a trial or support us financially.

We will use a number of metrics to track the effectiveness of the change over time.

What we do know is that putting KIDS at the heart of our name and our plan is resonating with our funders, collaborators and the community.





BUILDING FOR THE FUTURE

The new home of the Telethon Kids Institute is rapidly taking shape within the Perth Children's Hospital on the campus of the Queen Elizabeth II Medical Centre in Nedlands.

Already we have had a sneak peak at the amazing views across the city, Kings Park and the river that will be enjoyed by staff, patients and visitors.

Construction of the base building is well advanced and construction of the Telethon Kids fitout will commence in the second half of 2014. The new building will be ready for occupation at the end of 2015.

Leading Australian firm Woods Bagot was appointed as the architect for the Telethon Kids fitout project and has been working closely with our staff on the detailed design.

Our new facility will have nearly double the floor space of the existing Institute and will be situated on the top two levels of the Perth Children's Hospital.

There will be more than 2,200m² of state-of-the-art laboratories and the workplace design has been developed to create an environment that is engaging, promotes collaboration and provides the platform for world class research. There will be an interactive exhibition space on the ground floor of the hospital to promote and showcase the research activities.

The Institute will also enjoy a host of collaborative spaces on the fifth floor of the building including an auditorium, seminar and training rooms and a cafeteria.

The new Telethon Kids Institute has been made possible by generous funding from the State and Federal Governments.



D-Light

OUR GOAL | To provide the evidence base to improve the health and wellbeing of children through better understanding the breadth and magnitude of the risks and benefits of sun exposure

Sun exposure is about risks, benefits and balance.

And when you live in one of the sunniest climates on the planet, with the highest skin cancer rates in the world, it's important that we understand the roles that sunlight and vitamin D play in our health.

But there are still many unanswered questions.

What is the 'right' amount of vitamin D for good health?

What are the best ways to get vitamin D?

Do all of the benefits of sun exposure come through vitamin D or are there other pathways or chemicals that are triggered by sun exposure?

How much sun exposure is healthy and how much is dangerous?

Vitamin D is found in small amounts in some foods like oily fish and eggs. You can also boost levels through supplements but the best source is exposure of skin to the sun.

D-Light program co-leader Professor Robyn Lucas explains.

"You don't get much vitamin D in food," she says. "In Australia, we get most of our vitamin D through exposure of our skin to the sun. Vitamin D is made quickly when you go out in the sun, so you don't have to be out for long - 10 to 15 minutes every day, or even several times of a day, should be enough during summer or on a sunny day, but you will need to be outside for longer in winter, or on days when there is not much sun."

Vitamin D is important for the health of our bones, to ensure they stay strong, but it may also be important for other aspects of our health, like maintaining a healthy immune system.

While sun exposure has its benefits, it's not without its risks and that's where the balance comes into the equation.

"The Institute has done lots of research on the benefits of vitamin D during pregnancy as well as how it can help asthma and lung development," says Robyn. "But we need to look deeper into the risks of sun exposure especially with the high rates of melanoma we have here in Australia."

Professor Prue Hart, D-Light co-leader, says our past and current research has generated new questions that now need to be answered.

"D-Light will bring all of this research together to help unravel these complex questions and bring us closer to better understanding how we can harness the benefits of sunlight and vitamin D for the health of Australia's children while protecting them from the proven dangers of too much UV," she says.

"It's an area of research which presents a huge range of possibilities."

Professor Hart is leading the PhoCIS Study, a world-first study looking at prevention of multiple sclerosis using UV-B phototherapy.

The Raine Study, which has been following almost 3000 kids from birth to adulthood, will delve further into the risks associated with low vitamin D levels in pregnancy and early life – how we can better understand these risks and how to prevent and/or manage them.

The SEDS Study examines vitamin D and non-vitamin D pathways from sun exposure to better health, and tests sun exposure advice as a management tool for mild vitamin D deficiency.

And we are working with the UWA Centre for Metabolomics to develop a world first protocol to measure salivary vitamin D, in order to establish levels of vitamin D deficiency in WA children – painlessly.

The D-Light Project brings together a community of researchers working across the spectrum of risks and benefits of sun exposure and from prevention to treatment. With a shared interest, we will work synergistically – pushing each other to new questions, new data sources, new understandings.

**28% of West Australians
are Vitamin D deficient
during winter,
13% during summer**



Children's Cancer

OUR GOAL | Discover new therapies to fight the most aggressive cancers in children

A diagnosis of cancer is every parent's worst nightmare.

Cancer is the number one killer of children due to disease in Australia. Leukaemia, brain tumours, melanoma and other rare cancers continue to shatter the lives of kids and their families.

Whilst treatment of the most common cancer in children - acute lymphoblastic leukaemia - now has a greatly improved prognosis, the same success has not been achieved for children with other cancers. And some cancers in kids are still fatal.

Dr Raelene Endersby, co-leader of the Children's Cancer showcase project, says the goal is to discover new therapies - therapies that are more effective and less toxic - to fight the most aggressive cancers in babies and children.

"Many children fail to respond to existing cancer therapies and these treatments often result in lifelong side effects for those that do survive," she says. "We not only want to increase survival rates, but quality of life after therapy too."

Raelene says cancers in children are very diverse diseases.

"No two people will have the same cancer," she explains, "and in fact, cancers in children are very different to cancers in adults, as are the ways these cancers respond to treatment."

Children can develop a wide range of cancers in different organs, such as leukaemia in the blood or tumours in the brain. Plus there are many different types of each cancers, such as the brain tumours medulloblastoma or ependymoma. Then within each specific tumour type, there are multiple different subgroups.

"These complexities make the cancers very difficult to treat," she says, "such that, no single drug or therapy will cure everyone's cancer."

"Our goal is that future therapies will be tailored and personalised for each patient," she says. "Our challenge is to better understand which patients need which treatment. Then we will be able to

make a significant difference."

Our researchers are working to understand the biology of individual cancers to identify weaknesses to target. We also want to understand why apparently similar cancer cells from individual patients respond differently to treatment. We can then test existing drugs, and new ones, to improve patient outcomes.

Our researchers do this using the cancer cell lines grown using a specialised technique that we have perfected in the lab. Cancer cells are grown from samples taken from patients who have had the disease. We can then test new treatments, like novel chemotherapy drugs, or immune-based therapies and measure how the cells respond. We also send the cells to our colleagues around the world so they can do even more research.

Telethon Kids Institute researchers belong to an international cooperative clinical trials collaborative known as the Children's Oncology Group. All of our scientists collaborate broadly with national and international experts in our fields with the common goal to get new treatments into the clinic.

Our brain tumour researchers are also the only paediatric cancer-focused group within the Brain Cancer Discovery Collaborative, a national group of six brain tumour research labs that spans four Australian states.

By working together, small pieces of the cancer puzzle can be pieced together to gain a better understanding of the bigger picture.

"There is still so much we don't know and understand about cancer," says Raelene. "New discoveries do happen on a regular basis and it's an exciting time to be at the forefront of these."

Raelene says these small milestones and achievements also give hope to the parents of kids battling cancer.

"I've had parents say to me that they've felt helpless when their kids are undergoing chemo or radio therapy," she explains. "But they walk past our building, and look over to see the lights on and scientists working in the lab and they feel that if we don't give up hope, they won't either."



On average,
three
Australian
children die
from cancer
every week

FASD

OUR GOAL | To improve prevention, diagnosis and interventions for Fetal Alcohol Spectrum Disorders (FASD) in Australia

No alcohol in pregnancy is the safest choice.

When a developing baby is exposed to alcohol in the womb, it can cause brain damage. The effects are known as Fetal Alcohol Spectrum Disorder (FASD) and they are permanent but preventable.

Kids with FASD can have neurodevelopmental disabilities including developmental delay and problems with learning, behaviour, and social and adaptive functioning. These can lead to secondary outcomes such as poor school performance, unemployment, substance abuse, mental health problems and trouble with the law.

For around 12 years, the Telethon Kids Institute has been looking at FASD and the effects of alcohol during pregnancy.

Our previous research has linked alcohol consumption in pregnancy with premature birth, low birth weight, birth defects, cerebral palsy, language delay, still birth, SIDS and other infant deaths. We've also developed a range of materials to help health professionals talk to women about alcohol consumption during pregnancy.

People affected by FASD and their families are at the centre of our research.

Professor Carol Bower says much of the research into FASD is in response to the community and is done in collaboration with the community.

"Consumer and community participation in research, and in particular alcohol and pregnancy and FASD projects, has increased over the past ten years," she says. "The community has played a key role in our projects looking at a diagnostic instrument for FASD and our evaluation of information and services for parents and carers of children with FASD."

Our FASD research is focussed around three key themes - prevention, diagnosis and interventions. Most of the projects being undertaken in our program of research are the first of their kind in Australia and, in some instances, the world.

FASD is preventable, and it's through the 'no alcohol is the safest choice' message that a huge positive impact can be made. Women need to know

not to drink alcohol in pregnancy. And those who care for women during their pregnancy, such as family members and health professionals, need to be equipped with the right information so they can support and advise.

Professor Bower says correct diagnosis of FASD is vital.

"We don't yet have the information to know the true extent of the problem of FASD in Australia," she says. "An Australia-wide standard national approach is needed so we can understand the prevalence and then develop appropriate strategies to tackle it."

The Telethon Kids will lead the implementation and evaluation of the diagnostic instrument developed for use within Australia. It is closely based on tools used in other countries.

Professor Bower says a diagnosis may also be a relief for parents.

"Some kids are considered naughty or slow to learn so it's a relief for parents to have a FASD diagnosis - it is not that their child won't but that their child can't," she says. "Parents can then understand and manage their child in different ways."

Through appropriate intervention, management, training and services, we can help to support children affected by FASD and their families, plus the professionals who work with the kids such as those in health, justice, education and community services.

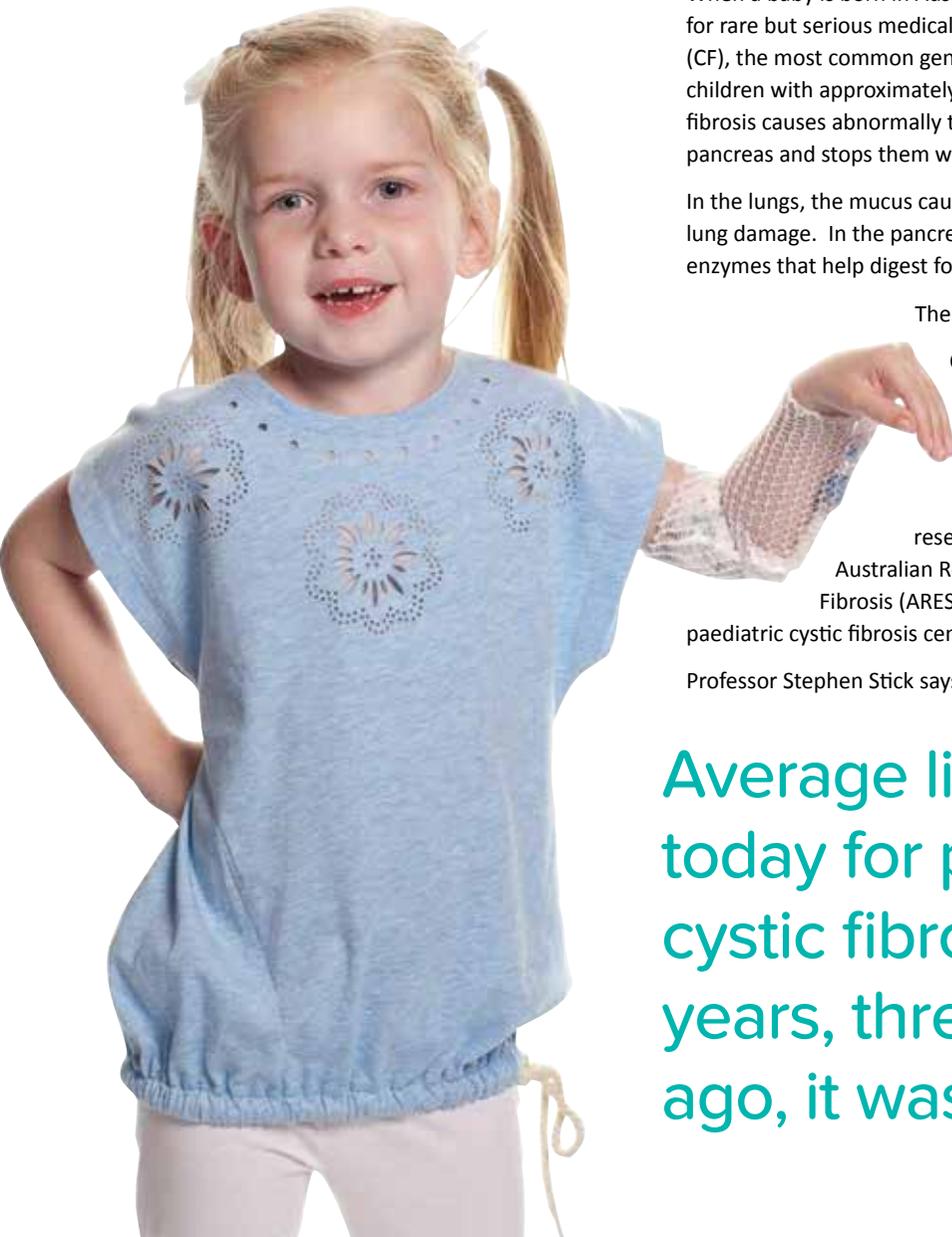
Together, we can make FASD history.

48% of women drink alcohol during pregnancy



Cystic Fibrosis

OUR GOAL | Extend life expectancy and quality of life by preventing early lung disease in children with cystic fibrosis



When a baby is born in Australia, a heel prick test is used to screen for rare but serious medical conditions. One of these is cystic fibrosis (CF), the most common genetic life-shortening condition affecting children with approximately one in 2500 babies born with CF. Cystic fibrosis causes abnormally thick and sticky mucus to clog the lungs and pancreas and stops them working properly.

In the lungs, the mucus causes inflammation, infection and irreversible lung damage. In the pancreas, it stops the release of important enzymes that help digest food and this leads to malnutrition.

There is currently no cure.

Once a diagnosis is made, doctors can begin the treatment programs needed to manage the disease, in particular to prevent the irreversible lung damage.

The Telethon Kids Institute runs a major research program in cystic fibrosis - the Australian Respiratory Early Surveillance Team for Cystic Fibrosis (AREST CF) - a collaboration between specialist paediatric cystic fibrosis centres in Perth and Melbourne.

Professor Stephen Stick says there are few specific treatments that

can prevent lung damage but that early identification and treatment if infection is critical.

“Antibiotics are very helpful for kids with CF, but they are not silver bullets,” says Stephen. “We’ve reached the limit with current therapies and new methods to treat the disease are needed.”

He says there is an opportunity right now for research to minimise the impact of the disease.

“A coordinated care approach has resulted in a doubling of life expectancy in the past thirty years,” he says. “But now is an exciting time when we have the knowledge and tools to make an even bigger difference for people with cystic fibrosis through better therapies.”

The AREST CF program has already changed the way clinicians around the world are thinking about the early management of CF. The program was the first to focus on early lung development in kids with the disease and to develop new ways of measuring the impact of therapies and interventions.

All children born with CF in Perth and Melbourne are part of AREST CF and researchers closely track their progress using a variety of often unique tools. The data gathered by the program have paved the way for a new pipeline of therapies.

With a focus on prevention of CF lung disease, Telethon Kids is using new “omics” technologies that allow unprecedented investigations of genetic and cellular structures. The program includes cell and molecular biology, physiology, psychology, drug discovery and stem cell biology to achieve practical interventions and inform clinical policies to improve the health of kids with cystic fibrosis.

Through a collaborative approach and dedicated focus, we hope to discover new drug therapies that can prevent and ultimately cure cystic fibrosis lung disease.

Average life expectancy today for people with cystic fibrosis is 49 years, three decades ago, it was mid-20s



ORIGINS

Chronic inflammatory noncommunicable diseases pose the greatest threat to human health globally.

Obesity, allergy and asthma, diabetes, mental health problems and heart disease are all complex with many interacting risk factors.

Professor Susan Prescott, leader of the ORIGINS project, says today's world presents new challenges and new problems in the area of health.

"The most burdensome health problems we face today have their origins in early life," she says. "So what happens in the womb or even our parent's health before conception can increase our risk of developing chronic health issues."

"To prevent them, we need to intervene early."

Susan says in particular, early environmental effects on very early immune and metabolic programming have life-long consequences for many organ systems.

"We need to look at all of the modifiable aspects of the early life environment such as nutrition, physical activity, time spent outdoors, smoking and pollutants, microbial diversity, water air and food quality," she explains.

"We then need to aim our interventions at these factors if we want to improve all aspects of physical and psychological wellbeing, both in childhood and in later life."

It's a big picture study, but one that will influence the health of generations to come.

"The current generation of kids could be the first generation to have a shorter life expectancy than their parents," says Susan, "simply because of obesity and the resulting noncommunicable diseases that being overweight or obese can cause."

"It's time to think outside the box, work together more

OUR GOAL | To reduce the rising epidemic of non-communicable diseases such as obesity, heart disease, allergies and poor mental health - through a healthy start to life

collaboratively and focus on early interventions."

Susan says the Western Australian Pregnancy Cohort (Raine) Study has taught researchers a lot about what we can do when we work together.

"We can take the lessons learned from the Raine Study and other existing cohort studies to extend the knowledge frontier to explore the new and different challenges facing the generation of children today," says Susan.

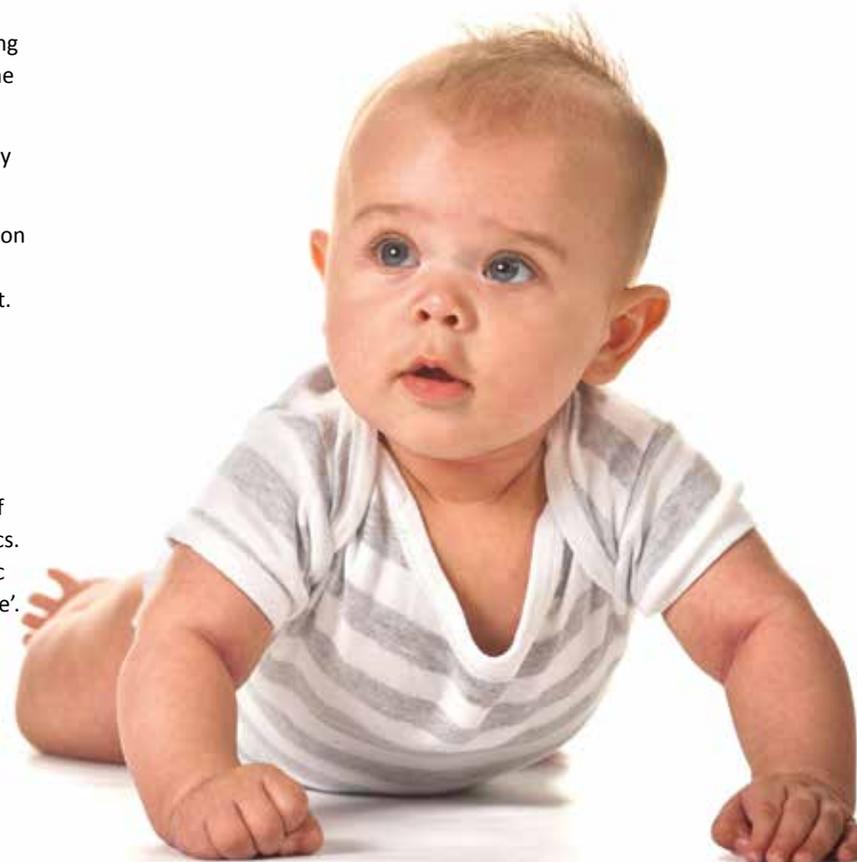
This will involve establishing a major new birth cohort with detailed data and sample collection, including more detailed environmental and early biological profiling (using cutting edge technologies such as metagenomics, immune profiling, metabolomics and genomics).

"And we won't just be observing," says Susan. "This study will also be about making change."

Within the cohort, we'll also initiate a series of intervention studies aimed at improving a broad range of health outcomes by favourably modifying the early environment. A clinical trial aimed at improving maternal gut health in pregnancy and lactation (with a mix of prebiotics 'fibre' and probiotics) to improve early metabolic and immune health of the developing baby is one such example.

Project ORIGINS aims to uncover when and why noncommunicable diseases develop through the study of early environments, maternal physical health and genetics. Our goal with this project is to reduce the rising epidemic noncommunicable diseases through 'a healthy start to life'.

Noncommunicable diseases account for 36 million deaths per year globally



Diabetes

OUR GOAL | New therapies that improve the lives of children and young people with Type 1 diabetes

Imagine a daily routine that involves pricking your finger up to eight times, working out how much carbohydrate is in everything you eat and then giving yourself injections with every meal and before you go to bed.

That's the reality for some of the 1000 West Australian children who live with Type 1 Diabetes. It's a 24 hour a day, seven day a week disease.

Type 1 Diabetes is not a lifestyle disease, it's not caused by poor nutrition or lack of exercise. Instead, the pancreas, a small gland behind the stomach, stops making insulin and without insulin, the body's cells cannot turn glucose (sugar) into energy.

Dr Elizabeth Davis says it's imperative that people with Type 1 Diabetes closely monitor their blood glucose levels throughout the day and night.

"It's really important that blood glucose remains within a good range so that health isn't compromised," she explains. "Hypoglycaemia occurs when levels drop too low and it can result in seizures, coma and even death."

"Constant monitoring can be a big burden for everyone," she says. "The person with Type 1 Diabetes needs to consider what they eat, exercise levels, medication they are taking and other lifestyle factors like stress and illness. And for parents, there is the anxiety that comes with getting up several times during the night to check their child's levels haven't fallen too low and they've gone into a coma."

People with Type 1 Diabetes depend on insulin injections to stay alive. Around 40% of people have insulin pumps, which drip insulin into the body throughout the day, rather than by injection, but they still need to be programmed by the user.

Dr Tim Jones says the next generation of technology is Closed Loop Therapy which takes the decision from the patient to the machine.

"The Closed Loop Therapy acts like an 'artificial pancreas' that would assist people with diabetes to better manage their glucose levels," explains Tim. "The advantage of the system is that it requires less intervention by the patient, potentially alleviating the physical and mental burden associated with this chronic disease."

The system takes an insulin pump and makes it 'smarter' by adding a smart phone that does the thinking for the patient. In-hospital studies are already taking place but the ultimate aim is for it to be used at home over multiple nights.

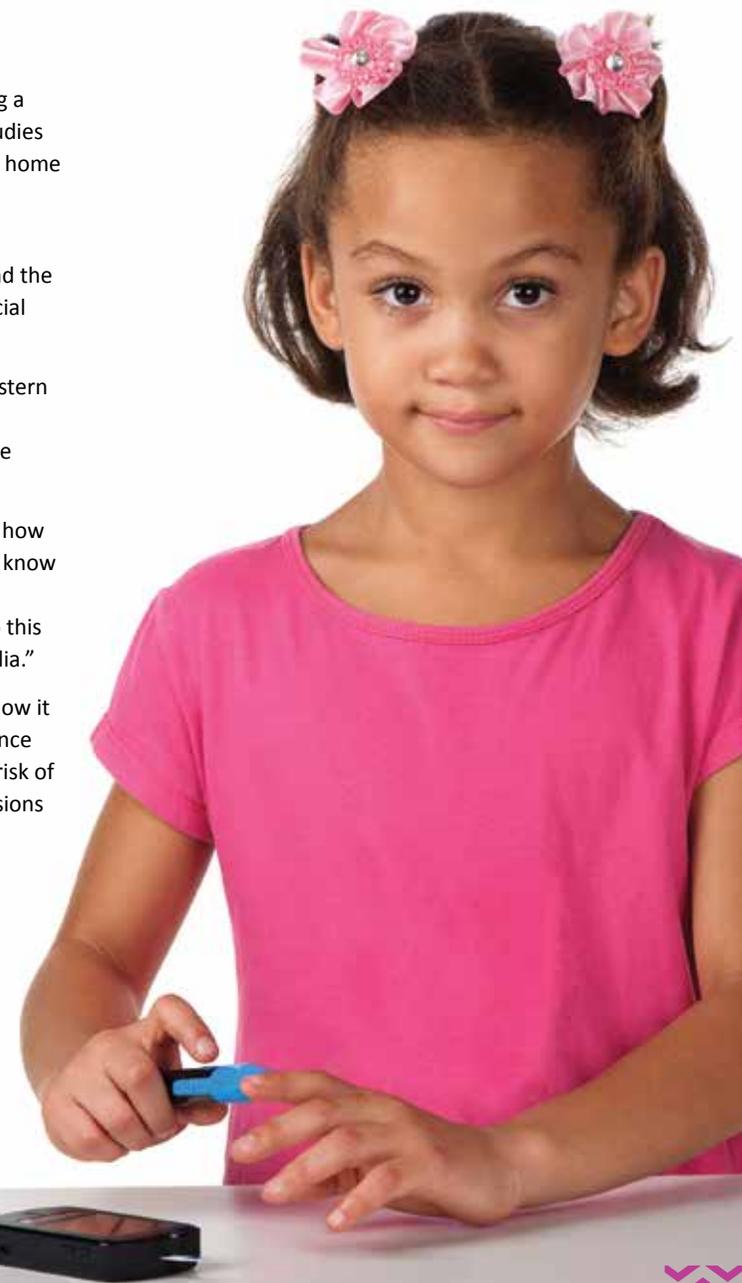
Our diabetes research team is the lead centre in these diabetes technology studies as part of the Closed Loop Therapy Program and the only Australian centre invited to be part of the International Artificial Pancreas Consortium.

By working with every child diagnosed with Type 1 diabetes in Western Australia, and their families, we can find out if new therapies are accessible and can learn more about factors that limit and promote everyday use of these new technologies.

"To improve patient care with technology, we need to understand how the technology works for them," explains Elizabeth. "We need to know that the technology is being embraced, used correctly and what is easy or difficult about it. Only then can we advocate for access to this technology for every child with Type 1 Diabetes in Western Australia."

The exact cause of Type 1 Diabetes is not yet known, but we do know it sometimes runs in families and cannot be prevented. In the absence of a cure, it is our aim to improve therapies so we can reduce the risk of long-term health complications, life-threatening coma and convulsions in kids and young people with Type 1 Diabetes.

Every week in WA, two kids are diagnosed with Type 1 Diabetes



Robyn Lucas

Professor Robyn Lucas is a problem solver.

She's driven by the need to take a problem, pull it apart and find the evidence around what works and what doesn't work. If that evidence doesn't exist, she then works out how to find the evidence to plug the holes in the problem, allowing the right decisions to be made and the right messages to be communicated.

It's a philosophy she applies to her research in the area of vitamin D and sunlight.

"There are many unanswered questions around sunlight, vitamin D and health," she explains. "The question that really intrigues me is whether all of the benefits of sun exposure come through vitamin D or are there other pathways that are triggered by sun exposure? There are a huge range of possibilities in this area."

It sees her working with people from many different areas, something she relishes.

"My research is very cross-disciplinary and that's what I love about it," she says. "With my work in sunlight and vitamin D, I get to work with physicists, nutritionists, plant scientists, immunologists, clinicians, biostatisticians and more. I've even learned a lot about the effects of UV on building materials and the UV transmitting properties of different types of glass! It really is an holistic approach to research."

Born and bred north of Auckland in New Zealand, Robyn started her career as a medical doctor after graduating from the University of Auckland. At 24, she went half way around the world to Canada to work in paediatrics. She moved to Canberra, married and spent the next few years between Australia's capital and the Pacific nations of the Solomon Islands and Fiji. It was in the Solomons that the first of Robyn's four children was born.

While in Fiji, Robyn completed a Masters degree by distance education, allowing her to balance work with a growing family. She says she fell into the area of vitamin D and sunlight during her PhD years, when she was asked to lead the Global Burden of Disease due to UV radiation assessment for the World Health Organization. She hasn't turned back.

Her research looks at risks and benefits of sun exposure and achieving a balance, with a particular focus on immune function and autoimmunity, and unravelling the possible independent effects of sun exposure and vitamin D. She has led a number of studies examining sun exposure and vitamin D status in relation to health and is currently involved in two clinical trials of vitamin D supplementation and one of UV radiation.

Perhaps it's Robyn's passion for problem solving that has drawn her to knitting, her favourite way to relax. Deciphering complex patterns, ensuring every stitch is in the right place and meticulous attention to detail has its parallels with research. Robyn is currently working on her third Great American Aran blanket, a gift for her daughter.



Stephen Stick

For Professor Stephen Stick, work isn't a chore, it's a passion. Even on weekends, if he's not out on the water or watching his kids play sport, he can be found reading the latest research, reviewing papers or writing grants.

Stephen leads the Institute's cystic fibrosis research program including AREST CF - Australian Respiratory Early Surveillance Team for Cystic Fibrosis. This unique program has been looking at early manifestations of CF lung disease with a focus on prevention to improve survival rates for kids with the disease.

He says it's an incredibly exciting time to be working in CF research as researchers at the cusp of making a big difference.

"Now is the time when there is a real opportunity to make a dramatic impact in cystic fibrosis," Stephen explains. "The knowledge and tools around cystic fibrosis are all coming together so it's exciting to be part of it."

Stephen likens it to times in the past when major developments have occurred in other areas of health and medical research.

"I imagine it feels like how polio researchers must have felt when they could see all the pieces of the polio puzzle coming together," says Stephen. "And in more recent times with cancer researchers, with the big gains made in childhood leukaemia survival rates."

Stephen has been part of research at the Telethon Kids for 20 or so years. Cystic fibrosis isn't his only area of interest - he's also interested in asthma, which he says is a fascinating disease with so many aspects, and other aspects of respiratory health and therapy. Paediatrics and respiratory health has always been an area of interest for Stephen.

He studied medicine at Cambridge University in the UK before specialising in paediatrics. He then moved out to Australia where he's continued his clinical career in the respiratory department at Princess Margaret Hospital for Children.

Stephen says he's been fortunate to have had a succession of inspiring mentors to keep his passion for research and medicine alive, including Professors Lou Landau, Peter Sly and Peter Le Souef.

But for Stephen, it doesn't take much to fuel the work fire. He says he doesn't feel the need to achieve a work-life balance because he loves his work.

"I'm passionate about my work, it's my life," he says.

But he also loves spending time with his family, and is passionate about travelling and reading.

"I've got three kids," Stephen explains. "My eldest daughter lives in Melbourne and is getting married later this year and my 15-year-old twins keep us busy with all their sports which include soccer, hockey, surfing, running and ice skating."

"And I like to hit the beach to paddle my surf ski or go surfing."





Graham Hall

Professor Graham Hall says one of the best things about research is seeing his students and colleagues succeed.

For him, watching his team members grow and develop their own careers is incredibly rewarding and he enjoys the part he can play in mentoring them and helping them achieve their goals.

Graham is a paediatric respiratory researcher with a focus on lung growth and development in early life and the impact of respiratory disease on lung health.

It was during his science degree at Swinburne University in Melbourne that Graham decided where his future lay.

“I was always interested in research and particularly paediatrics,” he explains. “In the third year of my undergraduate degree, we were required to complete an industry-based placement. I spent my time in the neonatal intensive care unit at the children’s hospital in Brisbane. Working with doctors and nurses and the tiniest of babies really cemented my interest in this area.”

After completing his degree, Graham made the move to Perth to work as a research assistant with Professor Peter Sly here at the Institute. It turned into a PhD.

Europe beckoned and Graham was again on the move, this time settling in Switzerland. He spent two years looking at lung function and measuring early lung disease in kids at the children’s hospitals in Zurich, where he was based, and Bern. It also meant he was close to some of Europe’s best skiing.

Since 2003, Graham has been back in Perth. For seven years he was a senior scientist in the paediatric respiratory laboratory at Princess Margaret Hospital before starting up his own research lab at the Telethon Kids Institute.

Graham says what drives him is doing research that will help improve our understanding of lung disease in kids.

“All research is important, even if the results show that something doesn’t work,” he says. “It all contributes to helping us better understand that disease, it’s all part of the bigger picture.”

“But it is very satisfying when you can see the results of your work being translated into clinical care or policy or guidelines.”

One such example is Graham’s work in preterm babies and air travel. Almost a decade of research in this area has helped inform international guidelines that were released in 2012. “Almost all of the air travel guidelines for premie babies were based on research done here in Perth,” says Graham.

While the ski slopes of Switzerland are no longer on his doorstep, Graham still enjoys snowboarding and skiing, these days with his family. “I don’t get to hit the slopes too often but love getting back to Europe when I can, particularly Italy,” he says. “Locally, I do a bit of swimming and swam to Rottnest in a team a few years ago and have completed the Busselton Jetty swim a couple of times.”



Susan Prescott

Professor Susan Prescott has a very strong and deep sense of purpose. A paediatrician, immunologist, researcher, writer and painter, Susan wants to put everything she has to the best possible use, and she’s happiest when she’s doing something, be that working or creating.

“Writing and oil painting takes me into a creative space, one that is quite different from research,” she says. “I paint landscapes from my travels and I’m writing my third book with plans already for the fourth.”

Susan’s first book, *The Allergy Epidemic*, focussed on one of her main areas of research. Her second book, *The Calling*, follows the journey of her grandparents, medical missionaries in Japanese occupied China during World War II. They were her inspiration to study medicine.

“My grandmother Monica was one of the few women to study medicine in the 1930s,” says Susan. “And my love of research and academia has been inspired by my grandfather Sir Stanley Prescott, former Vice-Chancellor of The University of Western Australia.”

Susan is passionate about social justice, human development and the environment.

“I grew up in a family with a strong desire to contribute to improving the physical, psychological and spiritual health of our society,” she says. “I think that this sense of community commitment underpins everything I do and I want to play any part I can in the kind of transformational societal changes that are needed to overcome the many global challenges we face today. I see my work as one vehicle to follow this goal.”

Susan graduated with a medical degree from UWA in 1989 before specialising in Paediatrics and then sub-specialising in Allergy and Immunology. For the past 15 years, she’s worked as a paediatrician at Princess Margaret Hospital for Children in the allergy and immunology department.

Susan joined Telethon Kids in October 2013 but for her it felt like coming home. She spent three years here in the ‘90s completing a PhD on the developmental origins of allergy.

Today, Susan’s research interests are broad and ever-expanding with a particular focus on the developmental origins of health and disease.

“We now know that a substantial component of the risk of all noncommunicable diseases (NCDs) is programmed in early life,” Susan explains. “In particular, early environmental effects on very early immune and metabolic programming have life-long consequences for many organ systems.”

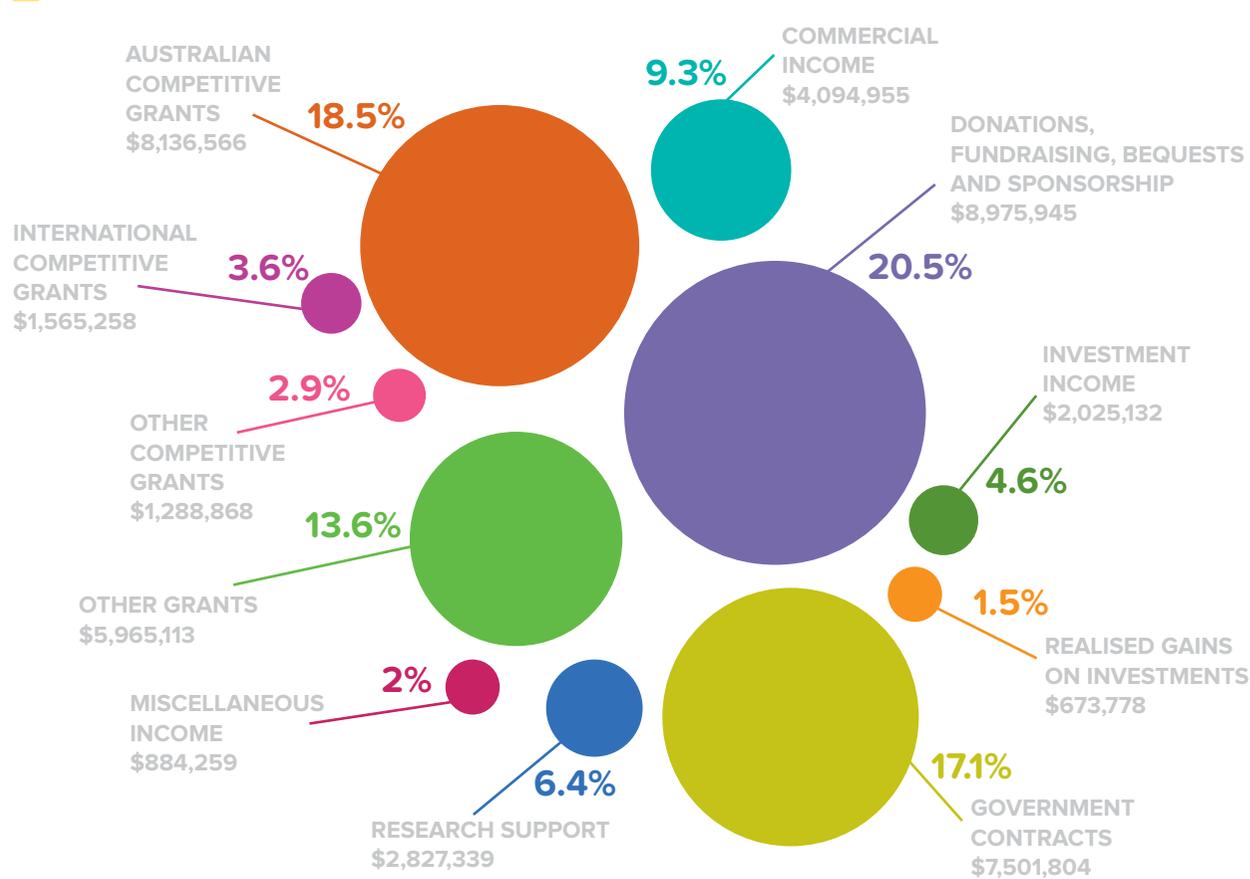
“As an immunologist, I’m particularly interested in the role of inflammation in the rising risk of obesity and associated NCDs - and the modern environmental risk factors that are increasing our predisposition to inflammation.”

“I’m interested in a range of strategies that promote a ‘healthier start’ to life (physical, psychological and social) in order to overcome the rising global burden of both early and late onset NCDs.”

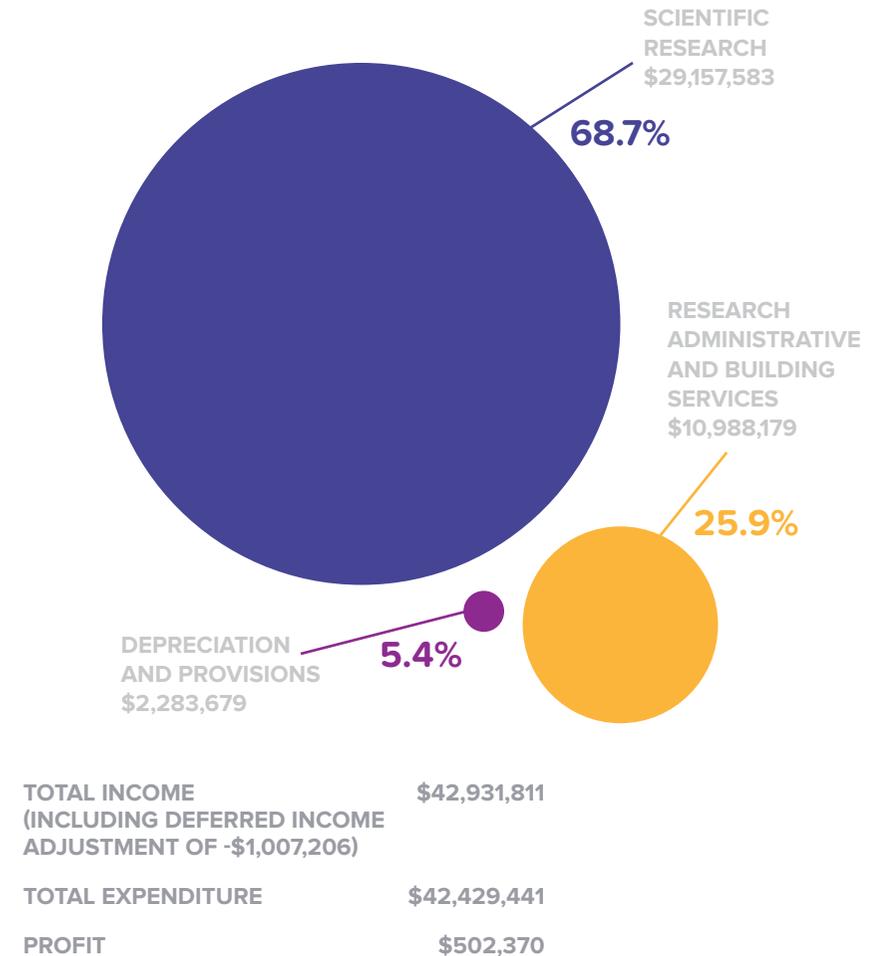


2013 SNAPSHOT

INCOME



EXPENSES



395 Total number of staff as at December 31 (paid and seconded)

110 Total number of postgraduate students during the year

123 Total number of honorary and visiting scientists during 2013



RESEARCH INCOME

AUSTRALIAN COMPETITIVE GRANTS

Australian Research Council	399,685
Australian Rotary Health Research Fund	31,765
Juvenile Diabetes Research Foundation	262,968
National Health and Medical Research Council	7,335,391
National Heart Foundation Australia	106,757

8,136,566

INTERNATIONAL COMPETITIVE GRANTS

Autism Speaks Inc	64,969
Cystic Fibrosis Foundation Therapeutics	437,160
Juvenile Diabetes Research Foundation International	597,598
Miscellaneous Overseas Grants	2,111
National Institutes of Health	462,026
Wellcome Trust UK	1,394

1,565,258

OTHER COMPETITIVE GRANTS

Asthma Foundation of Western Australia	20,489
Brightspark Foundation	219,839
Cancer Council of Western Australia	30,517
Children's Leukaemia and Cancer Research Foundation	860,050
Foundation for Alcohol Research and Education	5,918
Healthway	54,775
Melbourne Health	15,281
Raine Foundation	81,999

1,288,868

GOVERNMENT CONTRACTS

Western Australia	
Department of Health	1,680,521
Disability Services Commission	59,351
Office of Science and Innovation	62,470
Pathwest Laboratory Medicine WA	81,749
National Centre for Immunisation Research and Survey	26,265
Department of the Premier and Cabinet	70,000

Federal	
Cancer Australia	131,663
Department of Education, Employment and Workplace Relations	520,391
Department of Health and Ageing	3,613,148
Department of Innovation, Industry, Science and Research	856,848
Other	
Department for Education & Child Development, South Australia	399,398

7,501,804

COMMERCIAL INCOME

Aerocrine AB	20,000
Baxter Healthcare Pty Ltd	35,000
GlaxoSmithKline Australia Pty Ltd	133,160
GlaxoSmithKline Biologicals SA	3,107
INC Research Australia Pty Ltd	64,651
Medicines Australia Limited	14,000
Miscellaneous - Australian Commercial	6,000
Novartis Vaccines and Diagnostics Pty Ltd	99,839
Novo Nordisk Pharmaceuticals Pty Ltd	80,000
Novotech (Australia) Pty Ltd	43,348
OM Pharma	64,565
Pfizer Inc	20,129
Pfizer Pty Ltd	139,819
Phylogica Limited	3,258,209
Ondek Pty Ltd	72,328
Roy Morgan Research	34,193
Woodside	6,607

4,094,955

OTHER GRANTS

Asthma Australia Inc	58,801
Australasian Research Management Society	1,000
Australian National University	33,494
Australian Paediatric Surveillance Unit	177,474
Autism West Support Inc	36,195
Brain Foundation	20,000
Confederation of Meningitis Organisations (CoMO)	174,798
Curtin University	179,275
Edith Cowan University	20,000
Friends of the Institute for Child Health Research	11,518
Griffith University	8,000
Ian Potter Foundation	3,000
Lions Eye Institute	10,000
Lung Institute of Western Australia	50,000
Menziess School of Child Health Research	100,000
Miscellaneous	10,699
Murdoch University	13,500
Princess Margaret Hospital for Children	626,297
Princess Margaret Hospital Foundation	2,211
Ruah Community Services	19,944
Tasmanian Early Years Foundation	125,000
Thoracic Society of Australia & New Zealand	20,000
Uniting Care Children Young People and Families	10,000
University of Cambridge	17,840
University of Melbourne	30,000
University of Queensland	300,356
University of Sydney	83,797
University of Western Australia	3,725,553
Western Sydney Sexual Health Centre	15,400
Women and Newborn Health Service	18,075
World Heart Federation	62,886

5,965,113

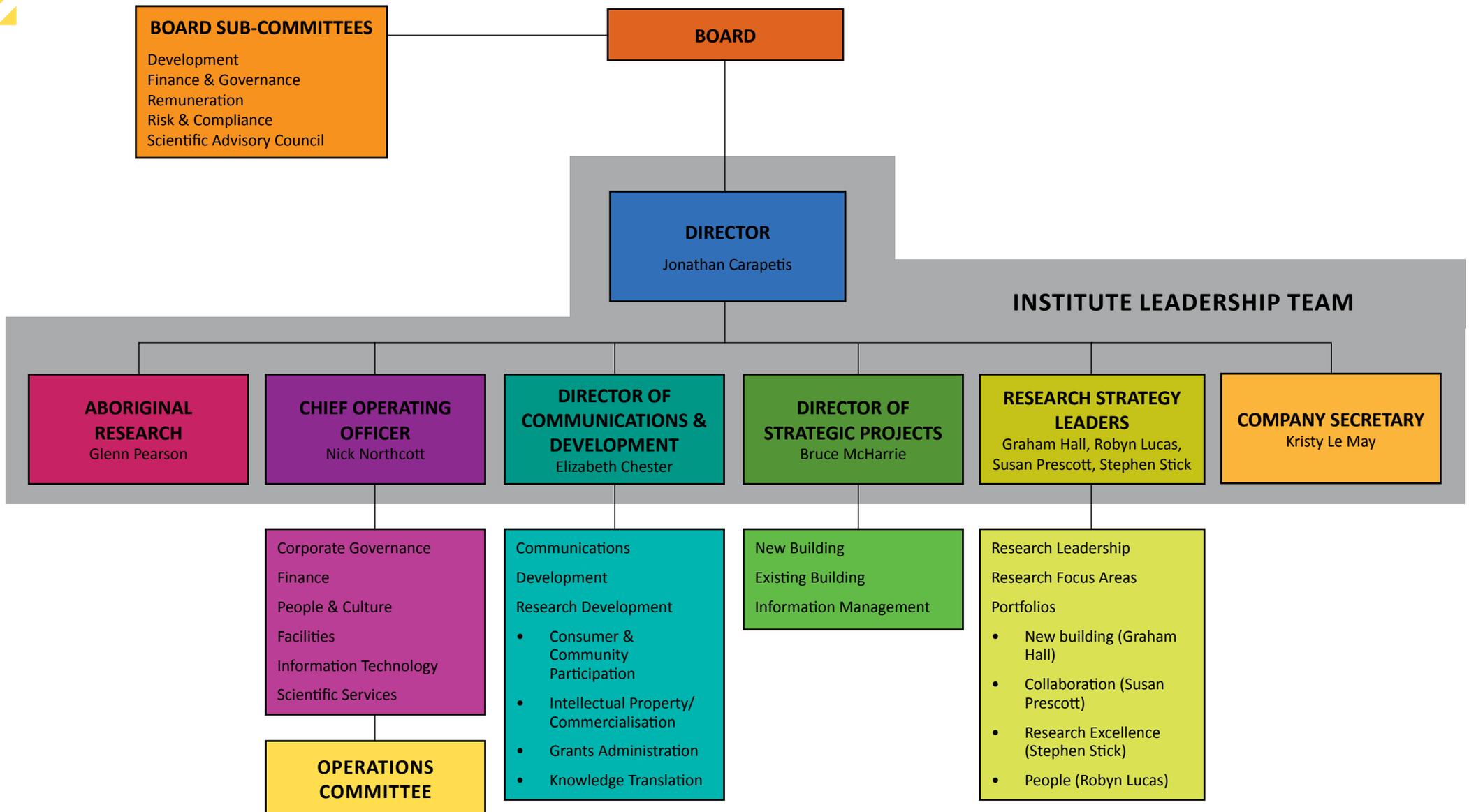
Miscellaneous income 884,259

TOTAL

29,436,823



GOVERNANCE/MANAGEMENT STRUCTURE





KIDS are at the 
of everything we do



For further information about donating to the Telethon Kids Institute, subscribing to our mailing list or joining us for a tour of our facilities please contact us on:

T | 08 9489 7777

E | contact@telethonkids.org.au

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