

Discover. Prevent. Cure

2016

TELETHON  
**KIDS**  
INSTITUTE  
Discover. Prevent. Cure.

ANNUAL REPORT



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**KIDS** are at the ♥  
of everything we do

**Right now in Western Australia:**

- one child each fortnight is fighting for every breath in intensive care due to **asthma**
- one in every 20 teenagers has major **depression**
- three out of four Aboriginal children in remote areas have **middle ear disease** which can affect their hearing and learning
- 5,000 children with **autism** cope daily with disabilities that rob them of their full potential
- parents of 1,000 children with **Type 1 diabetes** are apprehensive that when their children go to sleep at night, they might not awaken because of a dangerous plunge in their blood sugar
- 122 children are fighting **cancer** for their lives

It is for these children and their families, that we at Telethon Kids are committed to discovering causes, cures and treatments for these illnesses and diseases, and many more.

Our team of more than 500 dedicated researchers, students and support staff are passionate about research that makes a real difference so that every child has the very best opportunity to enjoy a happy and healthy childhood.

**Discover. Prevent. Cure.** Together, that's how we make a difference.

Find out more at  
[telethonkids.org.au](https://telethonkids.org.au)



Jonathan Carapetis (Director) & John Langoulant (Chairman)



## MESSAGE FROM THE CHAIRMAN & DIRECTOR

After three years of significant change and introduction of new programs to implement our Strategic Plan, the focus in 2016 was on consolidation and supporting the development and retention of our most important priority, our people. This has been particularly timely, given that as an organisation we are about to embrace another major transition with the move into our new facility within the Perth Children's Hospital in Nedlands.

### DEVELOPING OUR PEOPLE

In both our Strategic Plan and in feedback from our staff engagement survey, there has been discussion about the need for certainty of organisational structures, particularly for our researchers. Over the past year we have clarified the makeup of our research teams, headed by Team Leaders, who are then connected with research programs that sit within one of four Research Focus Areas (RFA). The Heads of each RFA have both a strategic and a management role, sit on the Institute Leadership Team (ILT) and report to the Deputy Director. The aim is to provide more effective line management support, career

progression and communication, while still supporting the wonderful collaboration and networking that the RFAs have brought to the Institute.

In our Professional Services, the Chief Operating Officer role has been split into Director of Corporate Services and Director of Research Services and Innovation, who together with the Director of Communications and Development report to the Executive Director and are also on the ILT.

Another theme that consistently arises is the retention and recruitment of "key talent". Our new Supporting Research Leaders scheme is a competitive process to retain, incentivise and support our best and brightest by providing salary underwriting for up to 5 years, in addition to a support allowance of \$100,000 for the top ranked applicants. We are delighted to have named Andrew Whitehouse, Anthony Bosco, Deborah Strickland, James Fitzpatrick and Tom Snelling as the inaugural Telethon Kids Leadership Fellows as a result of this process. This will be an annual call with applications rigorously reviewed by internal and external panels to ensure these Fellows are of the highest calibre.

In terms of strategic recruitment, we were very pleased to secure outstanding brain cancer researcher Professor Terrance Johns to head our Telethon Kids Cancer Centre. Professor Johns' research team is currently based at the Hudson Institute of Medical Research at Monash University. He has been making regular visits to Perth with the intention of moving his research program here later in 2017. We augmented this with the appointment of Dr Sebastien Malinge from France, who will also join us in 2017 as the Children's Leukaemia and Cancer Research Foundation (CLCRF) Fellow in Leukaemia Research.

Equity and diversity are priorities within our people strategy. We are already well into the implementation of our Aboriginal Employment and Career Development Strategy. We have also signed up to the Australian Academy of Science Athena SWAN pilot – an initiative of universities and research organisations to progress gender equity in STEM (science, technology, engineering, mathematics, medicine) fields. This is critical for an organisation like ours, with more than two-thirds of our workforce made up of women. As part of this, we have made efforts to ensure gender diversity on our main Institute committees (ILT, Institute Management Team, Scientific Advisory Council and Research Excellence Council). The Board is also undergoing a process of renewal to ensure that its own structure is informed by the same priorities.

## COLLABORATION

Collaboration is at the core of our Institute model. With the pending move to the Perth Children's Hospital, we have been pleased to be part of the formation of a Child Health Research Strategic Council, Chaired by Hon. Hendy Cowan, that is promoting a cross campus approach to excellence in research and the translation of knowledge from bench to bedside. There are a number of initiatives that are flowing from this, including the setting of a PCH campus research strategy and a centralised unit for supporting clinical research, generously supported by funding from Telethon.

Our relationships with WA's universities continue to grow with active research partnerships with all WA universities. Our strong relationships with UWA and Curtin University will be finalised during 2017 in new affiliation agreements that ensure mutually beneficial flows of research infrastructure and research outputs.

One of the most exciting developments has been the establishment in partnership with the Minderoo Foundation of CoLab – Collaborate for Kids, a strategic initiative to bring together community, researchers, policymakers and practitioners to improve the delivery of children's services and capacity of communities and

families to enhance the development and learning of all children, particularly those from low-income families. Under the Directorship of Professor Donna Cross, CoLab has undertaken extensive consultations within the sector to establish its strategic priorities and program of work.

In the north of our state, Telethon Kids Kimberley is gaining momentum. The vision is to build an ongoing presence and platform for sustainable, culturally appropriate and relevant research that brings positive change to the lives of children in the Kimberley. Of course this can't be done by just one organisation, and we are very pleased to be working in close collaboration with Aboriginal Health Council of WA, the Kimberley Aboriginal Medical Service, UWA's Rural Clinical School of WA, Notre Dame University, Rural Health West, and the WA Country Health Service to establish a hub of Aboriginal health research based in Broome.

## COMMUNITY

Once again there has been a strong focus on both engaging and involving the community in our research. Telethon Kids, together with the UWA School of Population Health, has been an international pioneer in the process of actively involving health consumers in the research process. Therefore, we were very heartened to see the program picked up by the WA Health Translation Network to enable its rollout more widely, thanks to significant funding from Lotterywest. Congratulations to Anne McKenzie and her team for ongoing leadership in this important field. A new Youth Advisory Committee has now been formed at Telethon Kids and we remain committed to this important initiative.

Giving back to the community that supports us remains critical. Our annual Discover Day doubled in numbers with a huge response from families despite terrible weather. We also hosted an expert panel on vaccination to respond to community questions on the issue. Unfortunately the event was over-taken by the anti-vaccination lobby, who prevented a rational discussion. However the resultant publicity and communication strategy meant we were able to get the information out to a far larger audience than we had initially envisaged. It demonstrates the important role of organisations such as ours in providing the evidence and discussion on scientific issues the community craves. In November we were privileged to host Professor Stephen Holgate, one of the world's most highly-cited biomedical researchers and a leading expert on respiratory health, for our annual community lecture. Professor Holgate's visit raised the profile of environmental pollutants as an important issue for child health and development and he was very generous in his time with our researchers.

## NEW BUILDING

Our move to a state of the art new facility at Perth's Children's Hospital has been significantly delayed. As has been widely reported, there were technical and contractual issues that meant the main hospital building was not completed within the projected time frame. The knock-on effect has meant that our builder, Multiplex, was not able to begin work on our fit-out until 2017. While there has been significant frustrations with the progress of the project, there is no doubt that the end result will be worth the wait. Credit must be given to our Head of Transition Don Koontz for his careful navigation through the various building and contractual issues. We very much appreciate the ongoing support of Richard Mann, John Hamilton and the Strategic Projects team and the Child and Adolescent Health Service Executive. We are hopeful of a move in early 2018.

Telethon Kids will retain ownership of the existing building in Subiaco that will be offered for lease. It is our intention to retain some of the space for a new initiative to provide research based clinical services.

## FINANCIALS

Some explanation should be made of the Institute's financial result for 2016. The Institute achieved a greater than anticipated surplus (profit from ordinary activities of approximately \$7.5 million) as an unexpected outcome as a consequence of the following requirements of financial reporting standards:

1. Receipt of approximately \$2.2 million in bequests, which has been allocated for strategic recruitment including Professor Terry Johns (mentioned above). Australian Accounting Standards required the funds to be recognised on receipt in the profit and loss statement.
2. Approximately \$3.4 million in funds that were already held on the Institute's Balance Sheet as "deferred income" were re-classified by our auditors as income earned during 2016 and transferred to the Statement of Profit and Loss following a comprehensive review of our Work in Progress balances. These funds had already been committed to additional child health research activities outside of the Institute's normal operational budget.

Not taking into account these extraordinary items, the Institute's underlying operating profit for 2016 was \$1,844,434.

## OUR THANKS

There are many to thank for the ongoing success and growth of Telethon Kids Institute. As Channel 7's Telethon prepares to celebrate its 50th anniversary, its commitment to us as our Principal Partner underpins our success. Our Strategy Enabling Partner BHP has supported the implementation of our strategic plan and our organisational reforms as well as supporting FASD research in the Pilbara. Wesfarmers, the Minderoo Foundation, the Children's Leukaemia and Cancer Research Foundation and The Adventurers all support significant programs of research. We are also grateful to Stan Perron Charitable Foundation, Cystic Fibrosis Australia, McCusker Charitable Foundation, The Kids Cancer Project, John Rothwell, Feilman Foundation and DR Capital for their major gifts towards our work. We have been humbled by those who have left a lasting legacy towards child research in their Wills, notably the estate of George Church, John Summers, Forrester Williams and Gwendolyn O'Driscoll. Indeed, our donor community has been passionate and generous supporters of Telethon Kids.

The voluntary service by the Directors on our Board is very much appreciated. We particularly thank Robyn Owens, Kate George, Michael Good and Michael Manford for their contributions as they step down and welcome new Directors Alex Brown, Jozef Gecz and Nicole O'Connor. We acknowledge the ongoing support and involvement of our Patron and Founding Director Fiona Stanley.

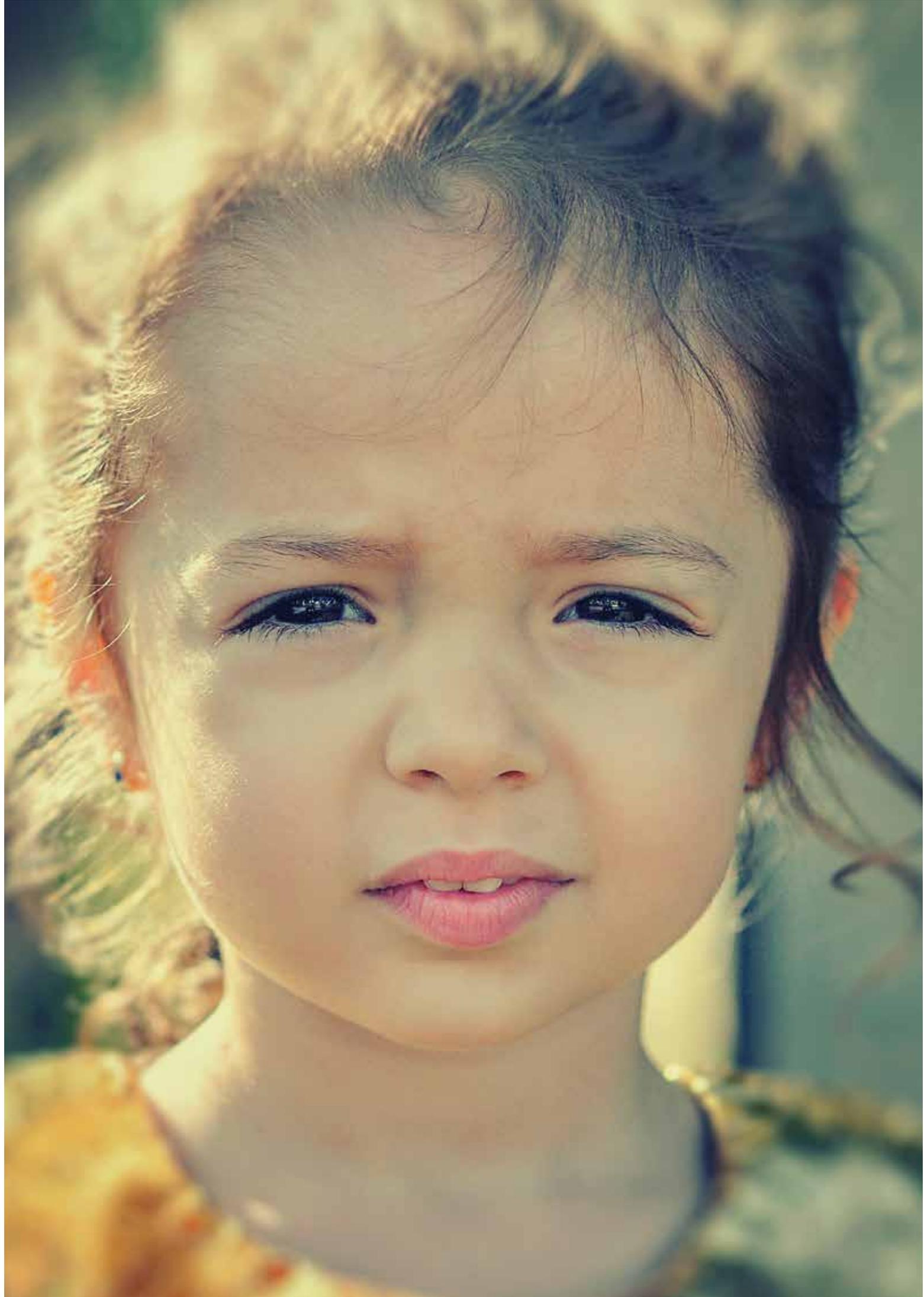
There is much to look forward to in the year ahead with the move to the new building and the consolidation of initiatives outlined in the strategic plan to create a new blueprint for a research institute. We pledged to be measured on the difference that we make to child health and wellbeing and encourage you to read our accompanying IMPACT report to see how we are delivering on that challenge.



John Langoulant  
Board Chair



Jonathan Carapetis  
Director

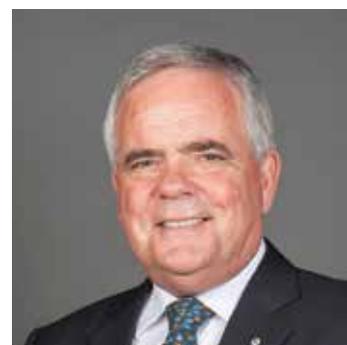


# **BOARD OF DIRECTORS**

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.

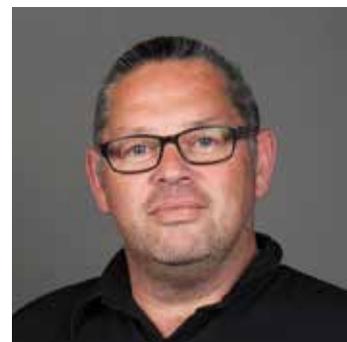
## **JOHN LANGOULANT AO (CHAIR)**

John became Chair of the Telethon Kids Institute in 2008 following his appointment to the Board in 2005. A respected business leader, John holds a number of board positions including Chair, Government Employees' Superannuation Board; Chair, Dampier to Bunbury Pipeline; Chair WA, Westpac Group; Chair, Pawsey Supercomputing Centre; Chair, Committee for Perth; and President, CEDA WA. John also consults to Curtin University and Deloitte. He also Chairs the Institute's Remuneration Committee, and is a member of the Finance Committee.



## **ALEX BROWN**

Alex is an Aboriginal medical doctor and researcher with an extensive and unique research program focused on chronic disease in vulnerable communities, with a particular focus on outlining and overcoming health disparities. Alex is the Leader of the Aboriginal Research Unit at SAHMRI and Research Chair of Aboriginal Health at the University of South Australia. He was recently admitted to the Australian Academy of Health and Medical Sciences and joined the Telethon Kids Institute Board in 2016.



## **JONATHAN CARAPETIS**

Jonathan took up the position of Director of the Telethon Kids Institute in July 2012. A leading paediatrician and infectious diseases specialist, Jonathan is recognised as a leading mind in the Australian health field, with particular expertise in Indigenous child health. He is a member of many state, national and international bodies including the Association of Australian Medical Research Institutes Board, NHMRC Australia Council, One Disease at a Time Foundation Board, WA Immunisation Strategy Implementation Steering Committee, Youth Justice Board, Australian Indigenous Doctors' Association, WA Health Translation Network Executive Board, Editorial Board Member of Heart Asia (British Medical Journal), and RHDAustralia Advisory Committee.



## **JOZEF GÉCZ**

Jozef joined the Board of Telethon Kids in 2016 and is also a member of the Institute's Scientific Advisory Council. Jozef is a NHMRC Senior Principal Research Fellow and Professor of Human Genetics at the Department of Paediatrics at the University of Adelaide, and established and heads the Neurogenetics Research Program at the Women's and Children's Hospital, Adelaide. He is a Fellow of the Australian Academy of Health and Medical Sciences.



Our thanks to Kate George, Robyn Owens, Michael Good and Michael Manford who all retired from the Board in the past year.



#### **JIM MCGINTY AM**

Jim joined the Telethon Kids Board in 2009 after stepping down from a long political career which included positions of WA State Health Minister and WA Attorney General. Jim is also on the Boards of Brightwater Care Group and Access Housing Australia, and is a volunteer with Fremantle Sea Rescue. He is also a member of the Institute's Finance Committee.



#### **NICOLE O'CONNOR**

Nicole joined the Telethon Kids Board in 2016 and is also a member of the Remuneration Committee. Nicole is General Manager Western Australia of SAP, a market leader in enterprise application software. Nicole is closely embedded into SAP's social programs for Young People – Young ICT Explorers & STEM – and is also the Executive Sponsor of the SAP's Business Women's Network in WA. Nicole is also as Board member of Fremantle Primary School, a Trustee of CEDA, and Member of both the Committee for Perth and the Australian Institute of Company Directors.



#### **JEFF DOWLING**

Jeff joined the Telethon Kids Board in 2009, bringing significant financial expertise as Former Managing Partner of Ernst & Young Western Region. Jeff is a Fellow of the Australian Institute of Company Directors, the Institute of Chartered Accountants Australia and the Financial Services Institute of Australasia. His board appointments include the West Australian Symphony Orchestra, Sirius Resources NL (Chair), St Andrews Insurance Ltd (Chair) and Metropolitan Redevelopment Authority. Jeff is also a Director of Atlas Iron Limited and Neptune Marine Services Limited. Jeff also Chairs the Institute's Finance Committee.



#### **MICHAEL McANEARNEY**

Michael is a Founding Director and Chief Executive Officer of Gerard Daniels. Michael joined the Board of Telethon Kids in 2012 and is also a member of the Institute's Risk and Compliance Committee and Remuneration Committee. Michael is a Member of the Australian Institute of Company Directors and the British Institute of Company Directors.



#### **ROHAN WILLIAMS**

Rohan accepted a position on the Telethon Kids Board in 2013 and also Chairs the Institute's Development Committee. Rohan is Executive Chairman of Dacian Gold Ltd and was the founding CEO and Managing Director of Avoca Resources Ltd prior to a merger in 2011 to form Alacer Gold Corp where he was a Non-Executive Director until September 2013. Rohan has worked extensively in the resources sector including with WMC Resources Limited where he held Chief Geologist positions at St Ives Gold Mines and the Norseman Gold Operation.

# 2016 HIGHLIGHTS



A study by Telethon Kids found Aboriginal mothers are at a significantly greater risk of preventable death than other Australian mothers and are much more likely to die from external causes, such as accidents, suicides and homicides, and they usually left more and younger children.

Cancer researchers at Telethon Kids discovered a new drug combination that could help improve survival rates for babies with leukaemia. The findings give new hope to babies under the 12 months of age who have poorer outcomes compared to older children.

Three Telethon Kids researchers were finalists in the 2016 Australian Museum Eureka Prizes.

**Dr Timo Lassmann** was as a member of the 'FANTOM5' Project that won the Scopus Eureka Prize for Excellence in International Scientific Collaborations.

**Professor Jonathan Carapetis** was a finalist for the 2016 CSIRO Eureka Prize for Leadership in Innovation and Science and

**Dr Tom Snelling** was shortlisted for the 2016 3M Eureka Prize for Emerging Leader in Science.

Lotterywest awarded a **\$3.2 million** grant

to the WA Health Translation Network to allow the highly successful Consumer Involvement Program of the Telethon Kids Institute and UWA School of Population Health to be expanded to 18 other WA organisations.

**Dr James Fitzpatrick** was named a finalist in the WA Australian of the Year awards for his work to reduce alcohol-related harm in babies.

Three outstanding Telethon Kids Institute researchers were named finalists in the 2016 Premier's Science Awards - Professor Carol Bower in the Scientist of the Year Award, Dr James Fitzpatrick in the Early Career Scientist of the Year category, and Tim Rosenow in Student Scientist of the Year category.

A new project, a partnership between the Telethon Kids Institute and BHP Billiton in collaboration with Wirraka Maya Health Services and the Hedland FASD Network, was launched in the Pilbara with the bold goal to make FASD history in the Pilbara.

Telethon Kids researchers, in collaboration with the National Centre of Immunisation Research and Surveillance, showed the protection children receive from their three baby doses of whooping cough vaccine starts to wear off after a couple years, leading to a toddler booster of the vaccine being added to the National Immunisation Schedule.

Researchers at Telethon Kids and the University of Sydney have developed Australia's first national diagnostic tool for Fetal Alcohol Spectrum Disorder (FASD).

A new state-of-the-art X-RAD radiation platform - the first of its kind in Australia - arrived in WA, allowing cancer researchers to access cutting edge technology to investigate ways to improve radiation therapy treatment. The equipment was funded by a \$500,000 grant from BHP with significant contributions from the Ian Potter Foundation, Chris and Tia Ellison, Telethon Adventurers, Tour de Cure, and Telethon Kids Institute.

A NHMRC Partnership Project grant will allow a collaborative team of researchers to track the progress of 12,000 from birth to age five to identify what services are valuable to families to support the health and wellbeing, education and care of their children.

The UK's Professor Stephen Holgate presented our Annual Community Lecture with a compelling presentation about how the air we breathe affects so much more than our lungs.



Telethon Kids Institute researchers were awarded more than

**\$10** million in research funding

from the National Health and Medical Research Council including seven project grants, two scholarships, four fellowships and Tropical Disease Collaborative Research Program.

The world leading Australian Autism Biobank, coordinated by researchers at Telethon Kids, was launched to collect detailed information on 5,000 children with Autism with the aim of identifying potential genetic and biological markers for autism, leading to earlier detection.

Telethon Kids was one of **six leading health organisations** to join the END RHD Coalition to **end rheumatic heart disease in Australia**, a condition that disproportionately affects Indigenous Australians.

Researchers from Telethon Kids and UWA found that young children living with an ongoing serious disease were up to **34 per cent more likely to be behind in their development.**

## Professor Donna Cross

was appointed Director of CoLab, hosted at Telethon Kids. **CoLab** brings together researchers with consumers, educators, leading clinicians, and other practitioners to improve service delivery to meet the needs of vulnerable children, families, and communities.

**Research from Telethon Kids showed a popular education program where teenagers care for a “robot” baby fails to reduce teen pregnancy, and could in fact increase the risk of pregnancy.**

In the world first study, researchers at Telethon Kids found **children with vitamin D deficiency are more likely to develop asthma**, showing repeated bouts of vitamin D deficiency in early childhood were linked to higher rates of asthma at aged 10, as well as allergy and eczema.

Telethon Kids Institute researchers have shown that a widely accepted test for diagnosing asthma may not be accurate in some settings, such as in screening defence force recruits and firefighters, with researchers urging caution in how the test is used.

Leading brain cancer researcher **Professor Terrence Johns** was appointed the Head of the **Telethon Kids Cancer Centre.**

**Researchers from Telethon Kids led the national Trans\* Pathways survey to investigate how we can better support trans and gender diverse young people.**

**Professor Alex Brown, Ms Nicole O'Connor and Professor Jozef Gecz** joined the Board of the Telethon Kids Institute. We thanked retiring board members Professor Robyn Owens, Professor Michael Good AO and Kate George who all made outstanding contributions to the Institute.

A grant from 100 Women will train 10 Aboriginal women from remote communities across the Fitzroy Valley as community health researchers while they work on a Telethon Kids project exploring long-term intervention for Fetal Alcohol Spectrum Disorder.

Telethon Kids Institute researchers found a **strong link between** excessive internet use and increased levels of psychological distress, including suicidal thoughts, in young people.

State-of-the-art 3D face scanning technology arrived at Telethon Kids to allow researchers to learn more about subtle facial differences in children with autism which may help with earlier identification and diagnosis of autism in children.

Telethon Kids Institute researchers received

**\$1 million**

from the FutureHealthWA program for research into better ways to treat skin conditions like skin sores and scabies in the Kimberley.

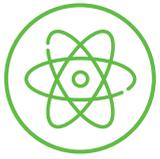
**Dr Gail Alvares from our Autism research team was named one the ABC's Top 5 Under 40 scientists in residence, giving her the opportunity to undertake a media residency at Radio National.**

The Telethon Kids Institute's Wesfarmers Centre of Vaccines & Infectious Diseases hosted **Hot Topics in Infection & Immunity in Children – Perth**, a clinical training course in childhood infectious diseases based on the successful ESPID-Oxford course.

**Results released from the Australian Early Development Census (AEDC), a population measure of how young children have developed by the time they start their first year of full-time school, showed that in 2015, most children in Australia were on track.**

Find out more at [telethonkids.org.au](http://telethonkids.org.au)





# INTRODUCING OUR IMPACT REPORT

Discover. Prevent. Cure.



**R**ight now at Telethon Kids, our researchers are working hard to discover, prevent and cure.

Research is an incremental process built over many years. It starts with developing a deep understanding of disease, working out how it might be tackled, implementing a possible solution and then evaluating it over time to see if cures, treatments or interventions have made a difference. This pipeline of research can take many years with many milestones along the way.

Our IMPACT Report highlights some of the research that is making a difference right now, those projects that are on their way to having a direct impact on kids and families, and research that is changing the way we think about these complex problems.

We also highlight some of the collaborative partnerships - with community, service providers, government, industry - that are helping us to have an impact locally, nationally and internationally.

|  |   |  |  |
|--|---|--|--|
| <b>TRANSLATION</b>   | <b>PARADIGM SHIFT</b>                               | <b>IN THE PIPELINE</b>                               | <b>COLLABORATING FOR IMPACT</b>                                      |
| This research has been actively translated into policy or practice | This research changes the very way scientists think | This research is in the pipeline towards translation | And this research shows how we work with others to make a difference |

## TRANSLATION.



### ROBOT BABIES INCREASE TEEN PREGNANCY RATES

Our research shows 'robot' babies, which have been used for decades to prevent teenage pregnancy, may actually increase it.

Sarah Johnson and Sven Silburn. Photo courtesy The West Australian.

## PARADIGM SHIFT.



### ELDERS INSIGHT LEADS TO SPINE-TINGLING BREAKTHROUGH

Working with distressed Nyoongar families to identify what's limiting their engagement with mainstream services.

Dr Michael Wright

## IN THE PIPELINE.



### DRUG FIND COULD REPRESENT BIG WIN FOR OUR LITTLE PATIENTS

The race to find a drug that will increase survival rates for babies with leukaemia.

Dr Rishi Kotecha with Jackson

## COLLABORATING FOR IMPACT.



### PARTNERING TO END RHEUMATIC HEART DISEASE

Teaming up with leading health organisations from around Australia and sharing expertise and knowledge to end RHD in this country.

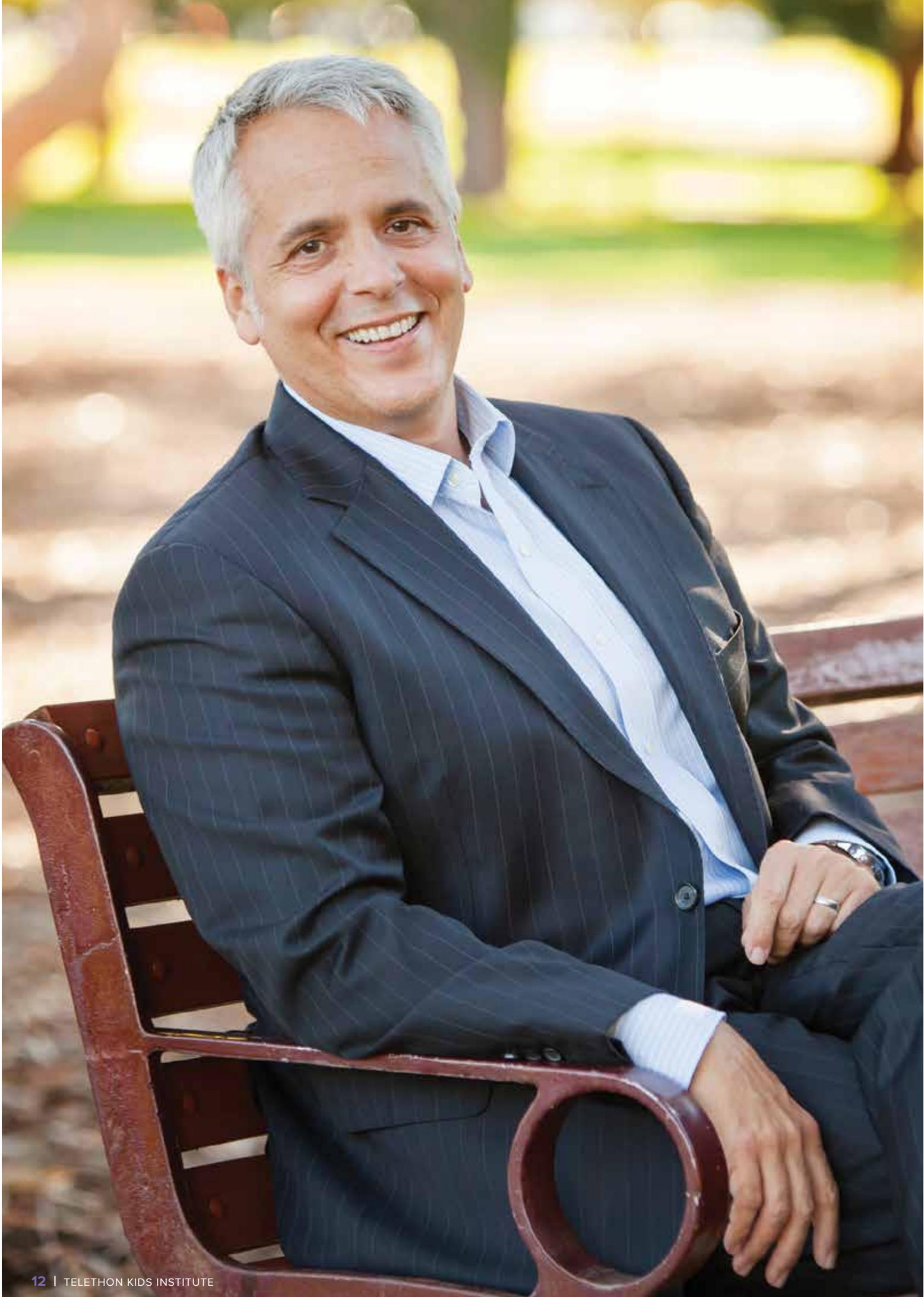
Professor Jonathan Carapetis with Laqueisha



Our IMPACT Report provides a snapshot of research at Telethon Kids and how it is making a difference.

You can request a hard copy by emailing us at [contact@telethonkids.org.au](mailto:contact@telethonkids.org.au) or phone 08 9489 7777.

Or download it now at [telethonkids.org.au](http://telethonkids.org.au)





# PHILANTHROPY REPORT

The most recent *NAB Charitable Giving Index* confirmed that 2016 was a difficult year for most charities across Australia. Western Australia had negative growth in charitable giving (-2.2 percent) due to a weakened economic environment. And, medical research charities had the lowest market share in WA, with just 3 percent of total donations (humanitarian services had the highest at 33 percent).

Against this backdrop, Telethon Kids fared well in one respect and less well in another. Donations from individuals, foundations and corporates increased by 5.6 percent. When combined with bequests, the increase in contributions was 19.6 percent. The Institute found, however, that individuals who normally give up to \$200 per annum found it financially difficult to do so in 2016, resulting in a (hopefully temporary) 25 percent decrease in their numbers.

The Institute is heavily reliant on philanthropy which accounts for some 32 percent of its income. In light of this dependence, the Institute would benefit from an increased understanding of the impact and importance of health and medical research to WA.

Child health and medical research saves and improves lives beyond measure. Our research helps to prevent children from becoming seriously unwell – a noble ambition in itself. Should these children be admitted to hospital, or seen at a local clinic, our research helps to ensure they have the best treatments and cures available. The Institute's research has the potential to change the world for children and their families.

It can also change the world for the adults these children will become, as most of the chronic diseases of adulthood have their origins in childhood. There are thus powerful economic as well as social reasons to promote the importance

of child health and medical research within the state.

For now, the Institute is honoured to have relationships with many of those who give to health and medical research. The Institute's philanthropic partners – whether individuals, families, foundations, corporates, civic groups, or schools – demonstrate a shared vision and commitment that is humbling and inspiring.

For example, they help the Institute directly address childhood cancer, infectious diseases, autism, teen depression, allergies, cystic fibrosis, rare diseases, asthma, early child development, nutrition, aggression, fetal alcohol spectrum disorders, and other urgent health issues in WA. Donors are crucially important collaborators in addressing these issues.

All donors, no matter their individual levels of giving, are equally important to the Institute. It is not by accident the Institute chose the light spectrum as its device for recognising donors within publications and on its donor board. Here, donors and their respective levels of contribution are organised by colours of the spectrum (red, orange, yellow, green, blue, indigo, violet). The message is that even as all bands of a spectrum are essential to the whole of producing light, so too are all bands of donors essential to supporting the Institute.

The Institute is grateful for and cherishes the relationships it has with its donors, engaging with them throughout the year personally and as a group. In the tough economic year that was 2016, these relationships sustained the Institute, and they will again in 2017.

**Tim McInnis**  
Head of Philanthropy



# DONOR HIGHLIGHTS



# BHP

**Stan Perron**  
Charitable Foundation

## Channel 7 Telethon

For a quarter of a century, Channel 7 Telethon has made an annual grant to Telethon Kids Institute that has been the Institute's lifeblood. Telethon's early support formed a chrysalis for the Institute, allowing us to fully emerge as a child health and medical research institute of international renown. We now flourish because of Telethon's annual commitment which, on behalf of the Western Australian community, helps us cover the total costs of research that we are unable to obtain from other sources. Being an independent research institute is not without its challenges, yet we are undeterred in our commitment to change the world for the children of WA and beyond. We are immensely grateful to have Telethon as our principal benefactor.

## BHP

In 2014, BHP made a five-year financial commitment to be the Institute's "strategic partner". They are providing the amount necessary for the Institute to make a strategic, capacity-enhancing investment that enables us to provide the very best research required by WA's children. Now, more than halfway through the five year partnership, the Institute has been able to retain and recruit world-leading scientists and a top professional services cadre while making improvements in such research platforms as bioinformatics, biostatistics, pre-clinical and clinical trials support, and bioresources. BHP's support extends beyond transforming the Institute into an ideal research environment. It also incorporates an initiative to encourage paradigm-shifting research by the Institute's researchers with a "Blue Sky" awards program, and an initiative to make fetal alcohol spectrum disorders history in the Pilbara.

## Stan Perron

Never before in Western Australia has a single individual made as great an impact to the overall health and wellbeing of children as has Stan Perron. Over the years the Perron Charitable Foundation has provided substantial funding support to Telethon Kids Institute and to our collaborating partners – Perth Children's Hospital and Cystic Fibrosis WA, for example. In 2016, Mr Perron made gifts to support the Institute's work in personalised medicine for children, cystic fibrosis research, and in Aboriginal child health research in the Kimberley. As well, Mr Perron and his family annually support a select number of PhD students whose research is being supervised by the Institute's scientists.





## Wesfarmers

The Institute has with Wesfarmers established the Wesfarmers Centre of Vaccines & Infectious Diseases which brings together researchers from throughout the State to deliver preventative strategies against infectious diseases, as well as new vaccines and diagnostic tests. Now in its fourth year, the Wesfarmers Centre is conducting research of global relevance at a pace that would not have been possible without the support of Wesfarmers. With their help, we are effectively addressing the under-immunisation of children in WA (particularly with respect to Aboriginal children), too many of whom die from vaccine preventable deaths or develop resultant chronic diseases in later life.



## Minderoo Foundation

The Minderoo Foundation has shown real leadership in establishing CoLab at the Institute. CoLab is a State-wide collaboration that focuses on encompassing vulnerable children 0-5 years of age with the developmental resources in the home and community that they need in order to be able to thrive by the age of five. Research conclusively shows that children who are not given strong developmental foundations in their earliest years are more likely to grow into adults who struggle due to underachievement in education, physical and mental health problems, unemployment, and criminal activity. CoLab is an exciting initiative that brings together families, clinicians, educators, policy makers and other practitioners and researchers to work together to ensure young children in Australia develop in order to thrive.



## Children's Leukaemia and Cancer Research Foundation (CLCRF)

It is highly likely that without the consistent support from CLCRF over three decades, there would not be a Telethon Kids Cancer Centre today. The CLCRF's contribution over that period of time has been some \$30 million and has underpinned the development of a comprehensive Cancer Centre at Telethon Kids that includes research programs in leukaemia, brain tumours, rare solid tumours, drug discovery, and prevention. These programs are founded on a collaborative ethos between scientists and oncologists at Perth Children's Hospital, spanning such areas as genetics, molecular biology, systems biology, immunotherapy, radiotherapy, surgery and epidemiology. CLCRF's remarkable legacy is relatively unknown to Western Australia in light of the Foundation's desire for a low public profile and insistence that the focus remain on children with cancer. We know, though, that those very children and their families would want CLCRF to know of their deep gratitude.



# WHO WE ARE AND WHAT WE DO

BOARD OF DIRECTORS  
PAGES 6-7

CHAIR  
JOHN LANGOULANT AO

INSTITUTE  
LEADERSHIP  
TEAM

DIRECTOR  
Jonathan Carapetis

as at June 2017



**ABORIGINAL HEALTH  
RESEARCH FOCUS AREA**  
Head, Glenn Pearson

Aboriginal Health is a Research Focus Area that aims to improve the health and wellbeing of Aboriginal children and families. This is an overarching priority for every Research Focus Area at the Institute. As there are specific cultural, social and economic contexts that require more specialised investigation in collaboration and consultation with Aboriginal families, this Research Focus Area is unique in that it provides advice, technical and cultural support across the Institute to all programs of research.

## RESEARCH FOCUS AREAS



**BRAIN & BEHAVIOUR  
RESEARCH FOCUS AREA**  
Head, Stephen Zubrick

**DEVELOPMENT & EDUCATION RESEARCH PROGRAM**  
Rebecca Glauert

ABORIGINAL HEALTH & WELLBEING  
Glenn Pearson

BIostatISTICS  
Nicholas de Klerk

CHILD HEALTH, DEVELOPMENT & EDUCATION  
Sally Brinkman

HEALTH PROMOTION & EDUCATION  
Donna Cross

LINKED ANALYTICS & SOCIAL POLICY  
Rebecca Glauert

**DISABILITY RESEARCH PROGRAM**  
Andrew Whitehouse

ALCOHOL AND PREGNANCY & FASD RESEARCH  
James Fitzpatrick, Roslyn Giglia

AUTISM RESEARCH  
Andrew Whitehouse

CHILD DISABILITY  
Helen Leonard, Jenny Downs

**MENTAL HEALTH & YOUTH RESEARCH PROGRAM**  
Francis Mitrou

ABORIGINAL MENTAL HEALTH &  
WELLBEING - LOOKING FORWARD  
Michael Wright

HUMAN CAPABILITY  
Steve Zubrick, Francis Mitrou, Cate Taylor

YOUTH HEALTH & WELLBEING  
Donald Payne



**EARLY ENVIRONMENT  
RESEARCH FOCUS AREA**  
Head, Deborah Strickland

**IMMUNITY & INFLAMMATION RESEARCH PROGRAM**  
Anthony Bosco

ALLERGY & INFECTIOUS DISEASE RESEARCH  
Belinda Hales

CHILD ALLERGY AND IMMUNOLOGY RESEARCH  
Debbie Palmer

EXPERIMENTAL IMMUNOLOGY  
Deborah Strickland

HUMAN IMMUNOLOGY  
Patrick Holt

INFLAMMATION  
Prue Hart

SYSTEMS IMMUNOLOGY  
Anthony Bosco

**INFECTION & VACCINES RESEARCH PROGRAM**  
Hannah Moore

EAR HEALTH  
Deborah Lehmann

GROUP A STREPTOCOCCAL AND  
RHEUMATIC HEART DISEASES  
Jonathan Carapetis

INFECTIOUS DISEASE  
IMPLEMENTATION RESEARCH  
Tom Snelling

INFECTIOUS DISEASES EPIDEMIOLOGY  
Hannah Moore

VACCINE TRIALS GROUP  
Peter Richmond

**DEVELOPMENTAL ORIGINS OF CHILD  
HEALTH RESEARCH PROGRAM**  
Roz Walker

THE ORIGINS TEAM  
Susan Prescott

ABORIGINAL MATERNAL HEALTH AND CHILD  
DEVELOPMENT  
Roz Walker

ALEX BROWN

JONATHAN CARAPETIS

JEFF DOWLING

JOZEF GÉCZ

MICHAEL McANEARNEY

JIM MCGINTY AM

NICOLE O'CONNOR

ROHAN WILLIAMS

DIRECTOR OF COMMUNICATIONS & DEVELOPMENT  
Elizabeth Chester

HEAD OF HEALTH PROMOTION & EDUCATION RESEARCH  
Donna Cross

HEAD OF CHRONIC & SEVERE DISEASES RESEARCH FOCUS AREA  
Elizabeth Davis

CO-HEAD OF BRAIN TUMOUR RESEARCH  
Raelene Endersby

DEPUTY DIRECTOR  
Graham Hall

COMPANY SECRETARY & HEAD OF CORPORATE GOVERNANCE & STRATEGY  
Kristy Le May

HEAD OF ABORIGINAL HEALTH RESEARCH FOCUS AREA  
Glenn Pearson

HEAD, INFECTIOUS DISEASE IMPLEMENTATION RESEARCH  
Tom Snelling

HEAD OF EARLY ENVIRONMENT RESEARCH FOCUS AREA  
Deborah Strickland

DIRECTOR OF RESEARCH SERVICES & INNOVATION  
Paul Watt

DIRECTOR OF CORPORATE SERVICES  
Nick Wood

HEAD OF BRAIN & BEHAVIOUR RESEARCH FOCUS AREA  
Stephen Zubrick

KULUNGA ABORIGINAL RESEARCH DEVELOPMENT UNIT

TELETHON KIDS KIMBERLEY



**CHRONIC & SEVERE DISEASES RESEARCH FOCUS AREA**  
Head, Elizabeth Davis

**CANCER RESEARCH PROGRAM**  
Paul Watt, Terrence Johns

**BRAIN TUMOUR RESEARCH**  
Raelene Endersby, Nick Gottardo

**CANCER EPIDEMIOLOGY**  
Elizabeth Milne

**CANCER IMMUNOLOGY**  
Jason Waithman

**DRUG DISCOVERY UNIT**  
Paul Watt

**LEUKAEMIA & CANCER GENETICS**  
Ursula Kees

**DIABETES & OBESITY RESEARCH PROGRAM**  
Shelley Gorman

**CARDIOMETABOLIC SUNHEALTH**  
Shelley Gorman

**DIABETES AND OBESITY RESEARCH**  
Tim Jones, Liz Davis

**GENETICS & RARE DISEASES RESEARCH PROGRAM**  
Timo Lassmann

**COMPUTATIONAL BIOLOGY**  
Timo Lassmann

**GENETICS & HEALTH**  
Jenefer Blackwell

**RESPIRATORY HEALTH RESEARCH PROGRAM**  
Alexander Larcombe

**AIRWAY EPITHELIAL RESEARCH**  
Anthony Kicic

**CHILDREN'S LUNG HEALTH**  
Graham Hall

**P4 RESPIRATORY HEALTH FOR KIDS**  
Stephen Stick

**RESPIRATORY ENVIRONMENTAL HEALTH**  
Alexander Larcombe

## PROFESSIONAL SERVICES

**DIRECTOR OF COMMUNICATIONS & DEVELOPMENT**  
Elizabeth Chester

**DIRECTOR OF RESEARCH SERVICES & INNOVATION**  
Paul Watt

**DIRECTOR OF CORPORATE SERVICES**  
Nick Wood

COMMUNICATIONS  
CONSUMER & COMMUNITY INVOLVEMENT  
DEVELOPMENT

INNOVATION & COMMERCIALISATION  
RESEARCH DEVELOPMENT  
RESEARCH GOVERNANCE & PLATFORMS

FINANCE & PROCUREMENT  
FACILITIES  
INFORMATION TECHNOLOGY  
PEOPLE & CULTURE

RISK AND COMPLIANCE

TRANSITION, NEW BUILDING

**TOTAL Staff**  
as at Dec 2016



**410**

**TOTAL Students**  
during 2016



**159**



# OUR FINANCIALS

## Our financial position in 2016

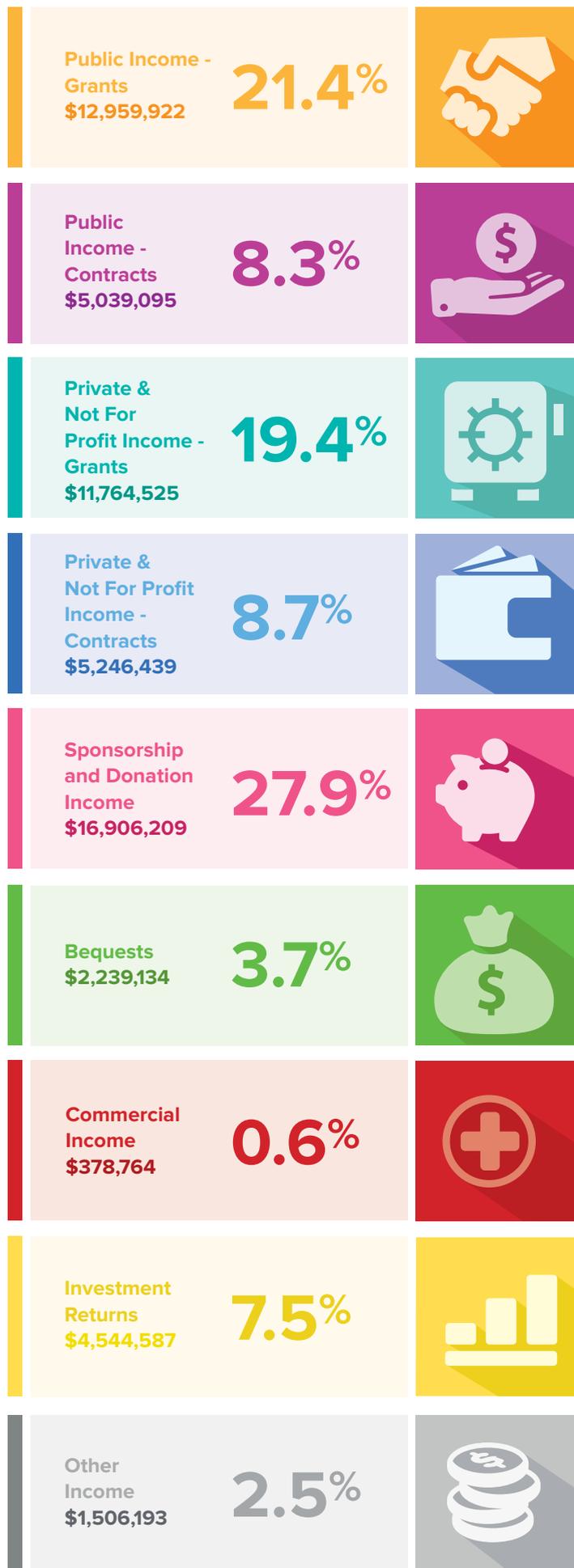
The Institute achieved a greater than anticipated financial result for 2016 (profit from ordinary activities of approximately **\$7.5 million**). This was an unexpected outcome which resulted as a consequence of the following non-routine inputs:

- 1 Receipt of approximately **\$2.2 million** in bequests. Bequests are an uncommon source of income for the Institute. With the unexpected receipt of these funds, our Board determined to fund the strategic recruitment of one of Australia's pre-eminent cancer researchers, Professor Terry Johns, for a five-year period. Professor Johns will lead the Institute's new Children's Cancer Centre. Australian Accounting Standards required the funds to be recognised on receipt in the Profit and Loss.
- 2 Approximately **\$3.4 million** in funds that were held on the Institute's Balance Sheet as "deferred income" were re-classified by our auditors as income earned during 2016 and transferred to the Statement of Profit and Loss following a comprehensive review of our Work in Progress balances. These funds had already been committed to additional child health research activities outside of the Institute's normal operational budget.

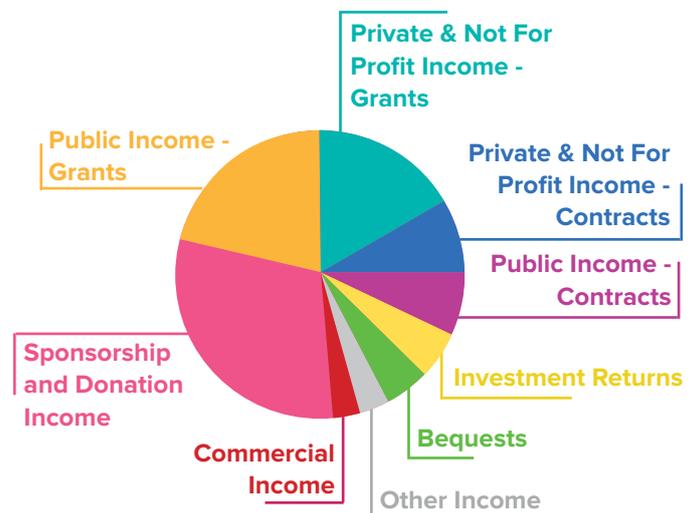
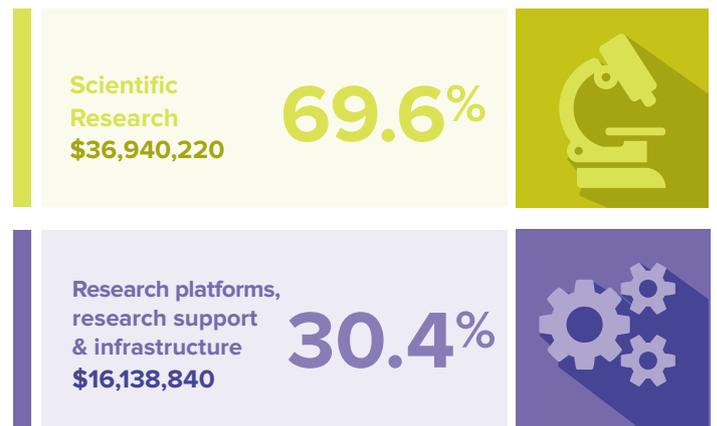
Not taking into account the abovementioned uncommon items, the Institute's underlying **operating profit for 2016 was \$1,844,434.**

Finally, it is relevant to highlight that there was a reduction in cash held by the Institute as at the end of the 2016 financial year by \$2,464,625. This reduction in cash reserves represents a continuation of the Institute's focus on expending accumulated funds in pursuit of specified research objectives as per our Strategic Plan.

## TOTAL INCOME \$60.5M



## TOTAL EXPENSES \$53M





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](mailto:contact@telethonkids.org.au)

**W** | [telethonkids.org.au](http://telethonkids.org.au)

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**KIDS**  
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100 Roberts Road, Subiaco Western Australia 6008  
PO Box 855, West Perth Western Australia 6872  
T | 08 9489 7777  
E | [contact@telethonkids.org.au](mailto:contact@telethonkids.org.au)  
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PRINCIPAL PARTNER



STRATEGIC PARTNER

