CONTENTS

MESSAGE FROM THE CHAIRMAN & DIRECTOR

BOARD OF DIRECTORS

2015 HIGHLIGHTS

OUR RESEARCH

WHO WE ARE AND WHAT WE DO

FINANCIALS
At the Telethon Kids Institute we are committed to research that makes a real difference.

We want every child to have the very best opportunity to enjoy a happy and healthy childhood.

Our team of almost 600 dedicated researchers and support staff are passionate about discovering causes, cures and treatments for the illnesses and diseases that target our kids and young people.

With top scientific minds and facilities, a reputation for being at the forefront of global child health research and a track record to prove it, Telethon Kids is world-class.

Yet we know that our work is even stronger when we work together. We are committed to collaboration. We create and facilitate connections with researchers, practitioners, service providers, our partners and the community, to maximise the potential in what we do and deliver tangible benefits to kids and families.

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

Find out more at telethonkids.org.au
2015 – YEAR OF SCIENCE

It may have seemed a bit unusual when we committed to 2015 being the year of science at Telethon Kids Institute — after all, you’d expect that’s always a key activity for a research organisation. However, in this year we wanted to raise it to a level well beyond business as usual. We wanted to enrich and elevate the quality of the research environment and, of course, the research itself.

In the previous year there had been an intense focus on the support structures that underpinned research that saw a transformation in processes and platforms across a range of areas including IT, bioinformatics, people and culture, research governance and grants management, marketing and fundraising. The benefits of that are tangible and ongoing.

So in 2015, as the Institute celebrated its Silver Anniversary, our focus was unashamedly on the science. As a result we can report on a number of exciting initiatives, many of them arising from the feedback from our first staff engagement survey.

The first is the development of the Research Excellence Council. This group of researchers from all levels across the Institute is charged with raising the research culture, quality and conversation within the organisation. Already they have reinvigorated the seminar series, run a fabulous Scientific Retreat, and will have significant input into research initiatives.

The second is the restructure of the Institute’s Scientific Advisory Council. The Council draws on the expertise of our most senior researchers and external members Professor Michael Good, Professor Jozef Gecz and Professor Sandra Eades to provide advice on research strategy, strategic recruitment and significant research infrastructure.

In addition to these councils, we have developed the principles for an underwriting scheme for leading researchers, to be implemented in 2016, and continued to grow our research centrepieces — the Research Focus Areas. These collaborative networks have continued to enable both internal and external engagement and sparked exciting research ideas. Some of these were funded by the very popular seed funding initiative and others, on the cutting edge of research, won support through the Blue Sky Funding Scheme. All this points to the successful development of an even more active and innovative research culture.

The impact of this focus on research quality and collaboration has a ready measure in grant success. From the National Health and Medical Research Council we were awarded a Centre of Research Excellence focused on Fetal Alcohol Spectrum Disorders and Telethon Kids-led applications won seven projects grants, totalling more than $11 million. Our overall success rate was 19 per cent, well above the national average. Already this year, the intensity and quality of grant activity has increased even further.

NEW RESEARCH INITIATIVES

As part of our focus on science, we have had a number of working groups and roundtables to develop larger, collaborative initiatives that
provide critical mass for researchers and distinct vehicles to attract diversified funding.

Without doubt, personalised medicine is the way of the future and was a priority for our 25th anniversary fundraising efforts. We were particularly honoured to host Professor Leroy Hood, a scientific luminary in this emerging field, to present our 25th Anniversary Community Lecture. He was an inspiration to all – from basic scientists to clinicians while capturing the imagination of our donors and the broader community. We have identified clear opportunities to apply this high tech approach in the paediatric sector and look forward to building stronger ties with Professor Hood’s International Institute for Systems Biology. Our thanks to the Stan and Jean Perron Foundation for providing start-up funding for this endeavour.

We were also very proud to launch a new Early Childhood Development and Learning Collaboration with support from founding funder the Minderoo Foundation. The Collaboration will bring researchers together with educators, clinicians, practitioners and community members to not only identify the evidence gaps in this crucial area, but to ensure that available evidence is provided in a way that is more accessible and practical. Professor Donna Cross has been appointed as the inaugural Director and eminent education researcher Professor Bill Louden has agreed to be the Independent Chair.

The increase in research activity in the State’s north has prompted the establishment of Telethon Kids Kimberley in Broome. This research hub, seed funded by Denby Roberts and the Wesfarmers Centre for Vaccines and Infectious Diseases, signals our strong intention to ensure a sustained program of work, based on building solid relationship with local communities and service providers.

FOCUS ON COMMUNITY

Our commitment to engaging and involving community, as outlined in the strategic plan, continues to grow. Our Consumer and Community Involvement Program led by Anne McKenzie continues to attract international recognition. Consumers are represented on each Research Focus Area and three new reference groups have been set up in the past year to inform diabetes, cystic fibrosis and ORIGINS research. To celebrate our Silver Anniversary, we threw open the doors of the Institute for an Open Day in October. The response was overwhelming with the building filled to capacity with families and children interacting with our researchers on a bunch of fun
activities. It will now become a regular part of the annual calendar. We are also embracing digital platforms to inform and engage with community about research issues including on social media. The effect of this is reflected in very positive brand awareness and engagement results.

NEW BUILDING

The new building project has consumed much time and energy of the Board and senior management over the past year. Delays to the Perth Children’s Hospital construction have had a knock-on effect on our fit-out, and it is now clear that we won’t be moving premises until well into 2017. There have been a number of contractual and tender issues that have been positively resolved. While the timing of our move is still to be confirmed, this extra time has allowed us to have even greater confidence that the new facility will be as dynamic and cutting-edge as first imagined. The State Government has shown commendable commitment throughout the negotiations to ensure a collaborative research environment for hospital, university and institute researchers to deliver the best outcomes for children and families in Western Australia and beyond.

OUR THANKS

This intense program of activities would not be possible without the extraordinary support of our Principal Partner Telethon and our Strategic Partner BHP Billiton. Their funding has underpinned our organisational transformation and directly enabled our research programs. It has meant that we can continue to recruit and retain outstanding research talent that is at the heart of our success. Wesfarmers’ ongoing investment in our infectious diseases research program provides more tangible evidence of how philanthropic funding can be leveraged to deliver even greater outcomes. Our Supply Partners initiative is another innovative way that business can support child health research. Our sincere thanks to all donors and partners who work with us to make a difference.

Our thanks to the Directors who serve on our Board and provide rigorous oversight to our operations. This year we farewell Kate George and recognise her significant contribution, particularly in working with the Kulunga Aboriginal Research and Development teams.

We acknowledge the passing of Professor Geoffrey Shellam who supported the Institute in so many ways since it began. Our hearts and thoughts are with our Patron, Professor Fiona Stanley. We also remember with great fondness Sir James Cruthers, the founder of Telethon, and good friend of the Institute.

Finally, our thanks to all the staff and students for contributing your intellect, ideas and commitment. Together we can deliver on our vision to improve the health and wellbeing of children through excellence in research.

John Langoulant
Board Chair

Jonathan Carapetis
Director
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, Committee for Perth; Chairman, Government Employees Superannuation Board; Chairman, Dampier to Bunbury Pipeline; Chairman, Pawsey Supercomputing Centre; President, CEDA in WA; 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; Member, WA State Health Research Advisory Council; Member, One Disease at a Time Board; Member, Program Management Committee, RHD Australia; Member, WA Youth Justice Board; Member NHMRC Australia Council.

JEFF DOWLING
Fellow, Australian Institute of Company Directors; Fellow, Institute of Chartered Accountants Australia; Fellow, Financial Services Institute of Australasia; Director, Atlas Iron Limited; Deputy Chair, WA Metropolitan Redevelopment Authority; Chair, S2 Resources; Non-Executive, NRW Holdings Ltd; Chairman, Pura Vida Energy Limited.

KATE GEORGE
Director and Principal Consultant, Claypan Services Pty Ltd; Director, Indigenous Business Australia Asset Management Pty Ltd; Graduate, Australian Institute of Company Directors; Member, Strategic Regional Advisory Council (Pilbara).
MICHAEL GOOD AO
NHMRC Senior Principal Research Fellow; Head, Laboratory of Vaccines for the Developing World, Institute for Glycomics, Griffith University; Member, Heart Foundation

MICHAEL MANFORD
Executive Chairman, Patersons Securities Limited; Chairman, Patersons Asset Management; ASIC Market Disciplinary Panel Member.

MICHAEL McANEARNEY
Director, CEO & Co-Founder, Gerard Daniels Australia; Director, Gerard Daniels UK; Member, Australian Institute of Company Directors; Member, Institute of Directors UK.

JIM MCGINTY AM
Board Member, Brightwater Group Inc; Board Member, Access Housing Association; 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, International Centre for Radio Astronomy Research Board; Member, National eResearch Collaboration Tools and Resources Project Board; Board Member, Astronomy Australia Limited; Board Member, Population Health Research Network; Member, National Committee for Information and Communication Sciences; Member, Australia Telescope Steering Committee; Member, EMBL-Australia Council.

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

ANNE KELSO served on the Board until March 2015
In 2015, we celebrated 25 YEARS of making a difference for kids and families!

We were awarded $1.2 million in infrastructure support funding from the WA Government.

Professor Michael Good AO, a NHMRC Australia Fellow at Griffith University, was appointed to our Board of Directors.

Together with the University of Sydney, we launched a $2.5 million Centre of Research Excellence to tackle Fetal Alcohol Spectrum Disorder.

New research revealed hormone levels in the womb may determine your facial features as an adult.

We launched the WA Children’s Diabetes Research and Education Centre for Research Excellence with $7 million in funding over five years.

We received $1.7 million in research funding from the Telethon-Perth Children’s Hospital Research Fund.

We were awarded $1.2 million in infrastructure support funding from the WA Government.

Our researchers received $11.3 million in competitive funding grants from the National Health and Medical Research Council.

We joined the Science in Australia Gender Equity pilot program to improve the promotion of women and gender minorities in science.

We found that current early intervention programs failed to identify a large proportion of children with language and literacy problems as performance can change at any time.

New research showed daughters born to older mothers have higher rates of some mental health problems.

We partnered with the Minderoo Foundation to create the Early Childhood Development and Learning Collaboration.

The Australian Research Council awarded our researchers $415,000 in funding to explore how testosterone levels in the womb can effect a child’s language development.

In 2015, we celebrated 25 YEARS of making a difference for kids and families!

We found that cases of spina bifida and related anomalies (neural tube defects) have dropped by 68 per cent since the mandatory introduction of folate in bread.
Our evaluation showed Tasmania’s Child and Family Centres are having a positive impact on parent’s use and experiences of services and support for young children.

We released the results from Young Minds Matter, the nation’s largest ever survey of the mental health and wellbeing of kids.

We developed a range of resources to help lawyers, judicial officers and other justice professionals to better deal with people impacted by Fetal Alcohol Spectrum Disorder.

We found the genetic variations that influence body mass index and diabetes in Aboriginal Australians are similar to those in non-Aboriginal populations, showing wide applicability of potential treatments.

We launched a world-class Centre of Research Excellence to find a credible path towards ending rheumatic heart disease in Australia.

Our consumer advocate Anne McKenzie was awarded a Member of the Order of Australia (AM).

We showed that children with Attention Deficit Hyperactivity Disorder had significantly worse school outcomes than children without the disorder.

Four of our researchers were awarded University of Western Australia Vice Chancellor Awards:

- Professor Jenefer Blackwell Senior Research Award
- Professor Andrew Whitehouse Mid-career Research Award
- Dr Tom Snelling Early Career Research Award
- Dr Kimberley Wang Early Career Research Award

Our cystic fibrosis research was a finalist in the Eureka Awards.

Cystic fibrosis researcher Professor Stephen Stick was awarded the prestigious Richard C Talamo Distinguished Clinical Achievement Award from the US Cystic Fibrosis Foundation.

Professor Carol Bower was awarded the International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR) Distinguished Service Award.

Dr Hannah Moore was named the Woodside Early Career Scientist of the Year at the Premier’s Science Awards.

With funding from Multiple Sclerosis Research Australia, we launched a new study examining the role of vitamin D in the risk of multiple sclerosis.

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Here at Telethon Kids, our dedicated researchers are passionate about discovering causes, cures and treatments for the illnesses and diseases that target our kids and young people.

Our **IMPACT Report** provides a snapshot of our research. Here, we’ve highlighted a few of the research stories featured in IMPACT.

Download it and find out more about how our researchers are making a difference at [telethonkids.org.au](http://telethonkids.org.au)

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**FOLATE WIN FOR ABORIGINAL BABIES**

After 30 years of hard work, Telethon Kids Institute researcher Carol Bower is celebrating the final confirmation of all that she ever dared hope for.
A NEW APPROACH FOR RESEARCH with ABORIGINAL COMMUNITIES

Winning the support of a remote Aboriginal community paved the way for a pioneering genetics study.

IN THE PIPELINE

TAKING ON A COMMON RESPIRATORY INFECTION IN KIDS

Mapping when a common childhood respiratory infection reaches its seasonal peak will assist how future vaccination programs are carried out.

COLLABORATING FOR IMPACT

IMPROVING THE LIVES OF KIDS WITH TYPE 1 DIABETES

Diabetes research got a huge boost when the WA Children’s Diabetes Research and Education Centre for Research Excellence opened late last year.
WHO WE ARE
AND WHAT WE DO

BOARD OF DIRECTORS
PAGES 8-9

INSTITUTE LEADERSHIP TEAM

DIRECTOR
Jonathan Carapetis

HEAD OF ABORIGINAL RESEARCH DEVELOPMENT
Glenn Pearson

DEPUTY DIRECTOR & ASSOCIATE DIRECTOR (RESEARCH)
Graham Hall

ASSOCIATE DIRECTOR (RESEARCH)
Stephen Stick (retired 2016)

ASSOCIATE DIRECTOR (RESEARCH)
Susan Prescott (retired 2016)

ASSOCIATE DIRECTOR (RESEARCH)
Paul Watt

RESEARCH FOCUS AREAS

ABORIGINAL HEALTH

BRAIN & BEHAVIOUR

CHRONIC AND SEVERE DISEASES

EARLY ENVIRONMENT

EXPERTISE AND TECHNOLOGIES

RESEARCH TEAMS
### Institute Management Team

**Chair:** Chief Operating Officer

- Communications
- Development
- Finance & Procurement
- Information Technology
- People & Culture
- Research Development
- Research Governance and Platforms
- Risk & Compliance
- Transition, New Building

### People Strategy Team

- Deputy Director
- Chief Operating Officer
- People & Culture
- People Leaders: Kim Carter, Glenn Pearson, Prue Hart, Kristy Le May, Francis Mitrou
# FINANCIALS

## TOTAL INCOME

<table>
<thead>
<tr>
<th>Source</th>
<th>Percentage</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australian Competitive Grants</td>
<td>16.7%</td>
<td>$8,923,421</td>
</tr>
<tr>
<td>International Competitive Grants</td>
<td>4.5%</td>
<td>$2,431,149</td>
</tr>
<tr>
<td>Other Competitive Grants</td>
<td>2.0%</td>
<td>$1,089,067</td>
</tr>
<tr>
<td>Government Contracts</td>
<td>11.4%</td>
<td>$6,108,297</td>
</tr>
<tr>
<td>Commercial Income</td>
<td>8.0%</td>
<td>$4,250,469</td>
</tr>
<tr>
<td>Other Grants</td>
<td>11.2%</td>
<td>$5,959,499</td>
</tr>
</tbody>
</table>

## RESEARCH INCOME

### Australian Competitive Grants
- Australian Research Council: $857,874
- Juvenile Diabetes Research Foundation: $970,736
- National Health and Medical Research Council: $7,094,811
- **Total**: $8,923,421

### International Competitive Grants
- Rett Syndrome Association UK: $8,318
- University of Pennsylvania: $20,121
- International Foundation for CDKL5 Research: $40,546
- Novartis Institutes for BioMedical Research: $175,234
- Cystic Fibrosis Foundation Therapeutics: $190,093
- International Rett Syndrome Association: $66,903
- Juvenile Diabetes Research Foundation Int (JDRF): $1,021,505
- Miscellaneous Overseas Grants: $28,412
- National Institutes of Health: $880,017
- **Total**: $2,431,149

### Other Competitive Grants
- Asthma Foundation of WA: $27,082
- Cancer Council of WA: $519,999
- Brightspark Foundation: $122,334
- Foundation for Alcohol Research and Education: $11,535
- Healthway: $214,614
- Melbourne Health: $21,393
- RAINE Foundation: $172,110
- **Total**: $1,089,067

### Government Contracts
- **Western Australia**
  - Department of Education: $18,019
  - Department of Health: $2,471,237
  - Disability Services Commission: $30,000
  - Mental Health Commission: $193,820
  - WA Commissioner for Children & Young People: $14,786
  - National Centre for Immunisation Research and Survey: $135,258
  - Department of the Attorney General: $24,601
  - National Disability Insurance Scheme Launch Transition Agency: $43,198
- **Federal Government**
  - Cancer Australia: $69,465
  - Department of Education: $1,776,292
  - Department of Health & Ageing: $1,006,134
  - Department of Industry: $25,000
  - Miscellaneous - Federal Government: $3,225
- **Other**
  - Dept for Education & Child Development, South Australia: $255,212
  - Department of Education, Tasmania: $42,050
  - **Total**: $6,108,297
Commercial Income
Sanofi-Aventis Australia Pty Ltd 99,777
BHP Billiton Iron Ore Pty Ltd 122,936
Joondalup Health Campus 150,000
Firefly Health Pty Ltd 3,255
inVentiv Health Clinical Pty Ltd 1,650
MedImmune Limited 21,750
GlaxoSmithKline Australia Pty Ltd 139,224
Johnson & Johnson Pharmaceutical Research & Development 41,487
Parion Sciences Inc. 166,947
Novartis Vaccines and Diagnostics Pty Ltd 14,773
Novo Nordisk Pharmaceuticals Pty Ltd 170,000
Pfizer Pty Ltd 80,569
Phyligica Ltd 3,176,112
Sanofi Pasteur 4,572
Ondek Pty Ltd 2,461
Novotech (Australia) Pty Ltd 54,956
4,250,469

Other Grants
True Blue Dreaming Inc 25,554
Women and Infants Research Foundation 10,000
Catholic Education Office - Sydney 40,000
CoMO - Confederation of Meningitis Organisations 50,742
Curtin University of Technology 96,491
Edith Cowan University 15,080
Friends of the Institute for Child Health Research 125,334
Ian Potter Foundation 252,500
Murdoch Childrens Research Institute 1,395

Total Research Income $29,315,467

INCOME
$50.3 MILLION

TOTAL EXPENSES

1.0%
30.0%
7.3%
7.9%
61.0%
39.0%

Miscellaneous Income $553,565
Donations, Fundraising, Bequests and Sponsorship $16,054,693
Research Support $3,887,813
Investment Income $4,199,498
Scientific Research $29,236,042
Research platforms, research support & operations $18,681,563

INCOME
$50.3 MILLION

TOTAL EXPENSES

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Investment Income $4,199,498
Scientific Research $29,236,042
Research platforms, research support & operations $18,681,563
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
W | telethonkids.org.au
are at the

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of everything we do