

# INSPIRE

RESEARCH AUSTRALIA SHOWCASES HEALTH & MEDICAL RESEARCH

## APHILANTHROPY FOCUSED ISSUE

---

The Role of  
Philanthropy in  
Rare Disease  
Research

---

Philanthropy  
& Government  
partner for patient  
self-management  
program

---

How cancer  
research benefited  
from generosity  
of the QUT  
community

**RESEARCH  
AUSTRALIA**  
CONNECTING • ENGAGING • INFLUENCING



# FOREWORD

A very warm welcome to the Summer edition of INSPIRE. Given the time of year, it seems fitting that we focus on celebration and giving – two key elements of the festive season.



And in that spirit, the recent Research Australia Awards was an incredible celebration of our country's great researchers and sector supporters from across the pipeline that we so proudly represent. The winners reflected this diversity and we thank the nominators for putting the highest calibre of nominations forward.

Especially noteworthy was the illustrious Peter Wills Medal, deservedly awarded to Professor Kathryn North AC from the Murdoch Children's Research Institute. As a paediatric physician, neurologist and clinical geneticist, Professor North's research and leadership contribution to Australia and internationally has been enormous. She is a role model for future generations and in no small way, driving the future of genomics today and for tomorrow. To hear more about her work, a must read is 'Pushing the envelope for the sickest of children' in this issue on page 24.

Giving back to the community, or the love of humanity as philanthropy is

often described, enables all sorts of possibilities in the world of research. The generosity of individuals and organisations is a vital part of the health and medical research and without it, much great work simply would not get done.

The winner of this year's Great Australian Philanthropy Award was Mrs Pamela Galli Trustee for the Lorenzo and Pamela Galli Medical Research Trust. This trust has provided critical funding leading to advances in skin cancers and child health, helping generations of researchers and patients as a testament to her late husband Lorenzo.

In a practical sense, the challenge of communicating the impact of research to donors, grant givers, government and philanthropists is real for many not-for-profit organisations and in fact for researchers themselves. Read on to hear how the Mater Institute in Brisbane faces that challenge on page 44.

As we hear from our Federal Health Minister, along with access, prevention and patient centred care, research is an integral pillar of our system. As this so called fourth pillar, it can help improve health outcomes for all of us. It can inform the delivery of better aged care, improve mental health, reduce chronic disease - giving families, giving us, the confidence that our loved ones are getting the best care.

Research is part of closing the gap for our indigenous community and the gap in rural, remote and socially disadvantaged communities. We must support foundational research that creates the bold ideas and then the new discoveries that are at the

genesis of the research pipeline.

It's important we continue to find ways to convert these ideas into better health, so we maximise the return on funding.

Speaking of return, a recent Economist article compared the difference between Gross National Happiness and Gross Domestic Product. It turns out

"...while increasing national income is important to happiness, it is not as important as ensuring a population is healthy. Importantly, and a one-year increase in longevity has the same effect on national happiness as a 4.3 percent increase in GDP.

It is this commitment to wellbeing and happiness that connects our vital sector and what drives our research, philanthropy and innovation and Research Australia takes its role as a whole of sector advocate, very seriously.

We were delighted to launch the 2019 Australia Speaks! consumer poll report at Parliament House and welcomed many members, political stakeholders and sector leaders. I encourage you to read the report and keep it on hand for reference. After all – it is the consumer's wellbeing that drives our work.

Please be sure contact us to input on your policy priorities so we include your voice in the broader alliance.

May I take this opportunity to wish you all the very best for a health and restful festive season and we look forward to hitting the ground running in 2020.

**Nadia Levin**  
CEO & Managing Director

# INSPIRE

RESEARCH AUSTRALIA SHOWCASES HEALTH & MEDICAL RESEARCH

INSPIRE is Research Australia's online publication showcasing its members' research, innovation and leadership.

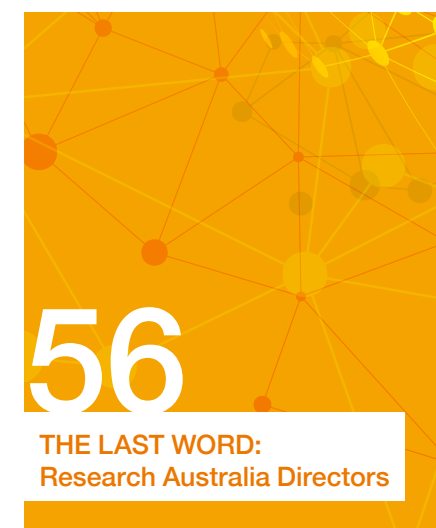
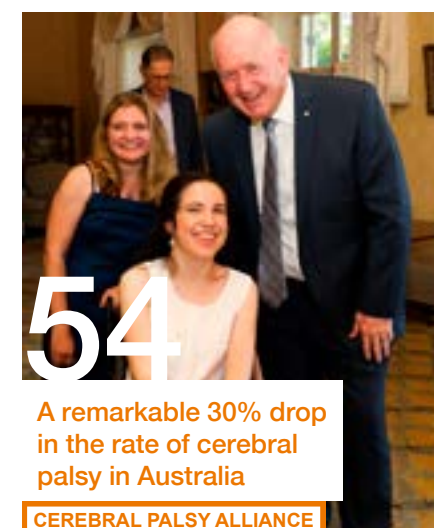
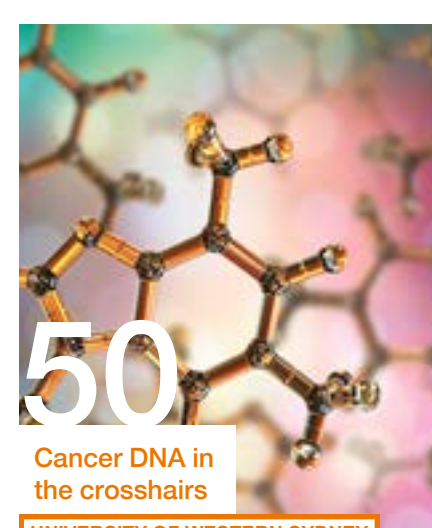
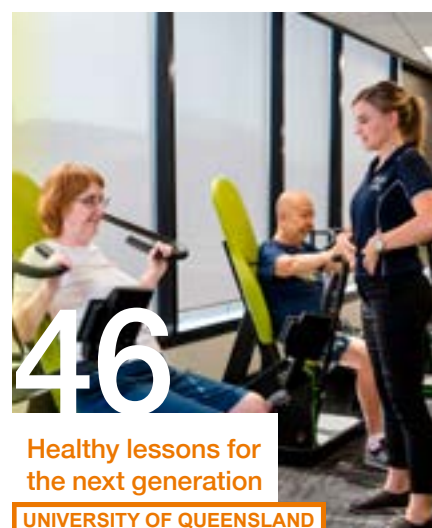
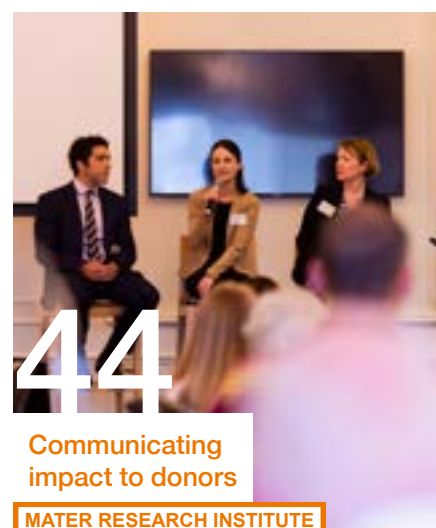
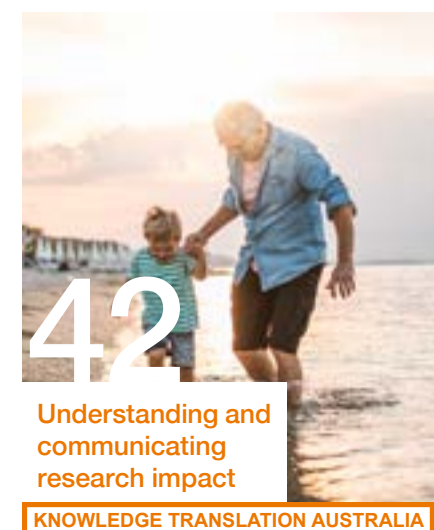
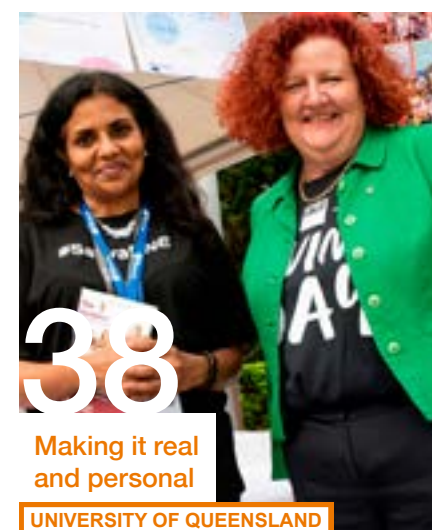
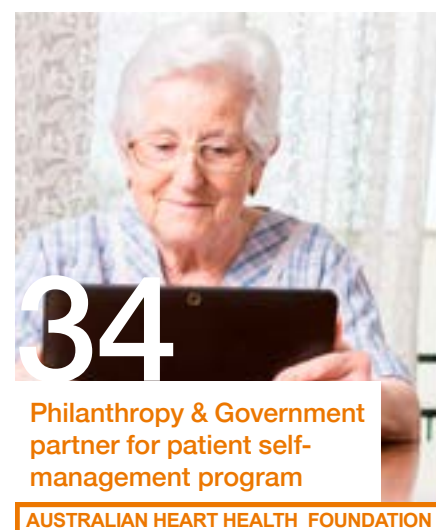
To view visit [researchaustralia.org](http://researchaustralia.org)





# CONTENTS

## Australian Health & Medical Research



**Publisher**  
Research Australia Ltd

**Art Direction**  
Matthew Ware  
p +61 403 844 763 or  
e matt@objktive.com

**For Advertising enquiries please  
contact the Research Australia  
office on**  
p 02 9295 8546 or  
e admin@researchaustralia.org

[researchaustralia.org](http://researchaustralia.org)



**INSPIRE ONLINE**  
[issuu.com/researchaustralia](http://issuu.com/researchaustralia)

INSPIRE is a publication of  
Research Australia Ltd  
ABN 28 095 324 379  
384 Victoria Street  
Darlinghurst NSW 2010

### Who can submit articles?

Any current member of Research Australia who would like to share a relevant story that affects their organisation including, philanthropic donations and their outcomes, research findings, and any other related health and medical research topic that affects the Australian population.

### Submission guidelines & deadlines

For information regarding how to submit and publishing deadlines visit the Research Australia [website](http://researchaustralia.org).

### Disclaimer

The opinions expressed in INSPIRE do not necessarily represent the views of Research Australia. Whilst every effort has been made to ensure accuracy, no responsibility can be accepted by Research Australia for omissions, typographical or inaccuracies that may have taken place after publication. All rights reserved.

The editorial material published in INSPIRE is copyright. No part of the editorial contents may be reproduced or copied in any form without the prior permission from Research Australia. © Research Australia 2019.



## EVENTS OVERVIEW

### UNIVERSITY ROUNDTABLE

The Research Australia University Roundtable on 25 September 2019 was held at Western Sydney University.

**Professor Barney Glover AO**, Vice Chancellor and President, Western Sydney University welcomed everyone to Western Sydney University. His presentation gave overview of WSU, and of the Western Sydney region, before addressing the Aerotropolis, Professor Glover described where it will fit within the region in relation to the University's existing campuses. The Aerotropolis, with its multiversity, will provide a new campus upon which the universities can collaborate. Professor Glover highlighted that the University is already working with University of Wollongong, University of Sydney, and UNSW Sydney, and the new campus at Badgery's Creek will provide the opportunity to expand and deepen these existing relationships.

### THE NORMING, STORMING AND PERFORMING OF INDIGENOUS RESEARCH

**Professor Auntie Kerrie Doyle**, Professor Aboriginal Torres Strait Islander Health, School of Medicine, Western Sydney University talked about the challenges and opportunities for both researchers and Indigenous communities in working together.

Aunty Kerrie explained the need to recognise the history of indigenous Australians and their experience with officialdom and as subjects of research. This has influenced contemporary responses to researchers and made people wary of imposition and interventions from outside.

Aunty Kerrie emphasised the need to take the time to engage with communities and to seek out the appropriate elders; recognising things are sometimes done differently in indigenous communities. Auntie Kerrie highlighted the importance of values: Integrity, Courage, Trust and Respect, in the initial development and engagement with communities and the undertaking of research.



### A NEW APPROACH TO CANCER TREATMENT AND RESEARCH: MRI-LINAC

**Professor Michael Barton OAM**, Scientia Professor of Radiation Oncology at UNSW, and Research Director of the Collaboration for Cancer Outcomes Research and Evaluation (CCORE) began his presentation with a brief history of radiotherapy and its use alongside surgery and oncology throughout the world.

Professor Barton went on to explain how the MRI-Linac fits within that history and global context. The MRI-Linac provides the opportunity for much more precise radiotherapy, targeting specific sites within tumours.

Professor Barton explained that the MRI-Linac at the Ingham Institute is one of only four machines in the world at the moment that can do this, and that each of the four has its own features, which are being explored to develop a better sense of therapeutic capabilities, minimum requirements and which features are the most useful/valuable. The Ingham Institute's MRI-Linac is currently undergoing further testing and development.

Professor Barton closed his presentation with an invitation to undertake a tour of the facility over the lunch break, which was accepted by several participants.

### FRUGAL INTERVENTIONS FOR PREVENTION AND BETTER CARE

**Professor Clara Chow**, Professor of Medicine, University of Sydney, Academic Director Westmead Applied Research Centre began with a brief description of the Westmead Applied Research Centre (WARC).

With a focus on chronic illness and a theme of embracing innovative research to improve patient and population health, it is focusing on simple, cost effective and scalable digital interventions to effect behavioural and lifestyle changes. WARC is currently undertaking 41 projects, of which it is leading 34.

Professor Chow outlined a couple of WARC's programs, and the results achieved. She also outlined WARC's approach to developing new interventions, emphasising the importance of a multistage process of development involving clinicians, public health experts, psychologists, and feedback from prospective participants.





## RISE OF THE INVISIBLES – TECHNOLOGY HIDING IN PLAIN SIGHT

**Associate Professor Paul Breen**, MARCS Institute for Brain, Behaviour and Development, Western Sydney University positioned his discussion of ‘invisible’ technologies by looking at the evolution of three old technologies: eyeglasses, hearing aids and pacemakers. In each case the technology has evolved to something that is less obtrusive/almost invisible (contact lenses and hearing aids) or is implanted in the human body (modern pacemakers).

Paul discussed the opportunities for new wearable technologies to be worn as clothing, and relatively cheap to manufacture using existing materials. They could be used for constant monitoring of multiple signals. He envisages the market is not for devices that would be worn constantly in everyday life, but as technologies that would be worn for extended periods of time to capture diagnostic data, e.g. respiration rates, heartbeat, Apnea-Hypopnea.

Paul closed with a discussion of some of the challenges which have much in common with other advances in HMR and technology, including data security, reliable network connectivity, power consumption of devices, big data management and analysis, and integration.

## POLICY UPDATE

**Greg Mullins**, Head of Policy, Research Australia provided a review of recent policy developments

## INVESTIGATOR GRANTS, GENDER EQUITY AND UNCONSCIOUS BIAS IN SELECTION

**Professor Kirsty Forrest**, Dean of Medicine at Bond University gave a short presentation on unconscious bias and its role in selection processes such as peer review in the context of the low numbers of Investigator Grants awarded to women.

Kirsty outlined the evidence of continuing gender and racial inequity in academia and the impact of unconscious bias, providing some examples. She then went on to outline strategies for addressing unconscious bias at the intrapersonal, interpersonal and organisational levels. She summarised the position:

- Everyone has unconscious biases and are, at times, affected by bias.
- Individuals have a responsibility to learn how to manage the impact of implicit biases on their behaviour and decision making.
- Leaders must raise awareness of unconscious biases amongst their followers and tactfully address or challenge undesirable behaviours.
- Organisations need to evaluate, assess impact, and take steps to mitigate biases within their policies, procedures and organisational culture.



Professor Auntie Kerrie Doyle, Western Sydney University

## 2019 AUSTRALIA SPEAKS! POLL REPORT LAUNCH – PARLIAMENT HOUSE 16 OCTOBER

**Research Australia** has been polling the Australian public since 2003. The outcomes from these polls have been widely read across and often quoted by Government to broad range of audiences. Each year a full report is produced with the key highlights from the consumer poll are and distributed through various channels including Research Australia members, government departments and the public. This event was a great success and well attended by sector leaders from across the entire health and medical research pipeline.

Award winning News Ltd Journalist Jane Hansen MC'd the event with the Hon. Greg Hunt giving the keynote address. Nadia Levin shared the key outcomes of the report highlighting the trends arising and interesting consumer opinions on various areas of health and medical research. Research Australia Director Professor Mary Foley AM spoke about improving health systems through health and medical research which was followed by a panel discussion on the empowered patient and consumer. Member representatives made up the panel and included Greg Johnson, CEO Diabetes, Michael Thorn, CEO of FARE and Jeppe Theisen, Vice President and General Manager Oceania, Novo Nordisk Australia.



The Hon Greg Hunt, Minister for Health & Nadia Levin CEO Research Australia



Above: Leanne Wells Consumers Health Forum, Michael Thorn FARE, Greg Johnson Diabetes Australia

Left: Panel Session: Greg Johnson, CEO Diabetes, Michael Thorn, CEO FARE & Jeppe Theisen, VP & GM Oceania Novo Nordisk Australia



# RESEARCH AUSTRALIA AWARDS 2019

HEALTH & MEDICAL RESEARCH

The 17th Health and Medical Research Awards was held in Melbourne at Metropolis Southbank, Thursday 14 November. 280 people gathered for the black tie dinner and award ceremony.

This year UNSW Sydney sponsored the welcome cocktail reception and we had four Award Category Sponsors, GSK, Griffith, Bupa Health Foundation and the Victorian Government. Other sponsors included Monash University and Ingham Institute and we thank them for their invaluable support.

As per tradition the event convened an audience of influencers from across the sector including: Research organisations; Health providers; Peak bodies; Academic institutions; Charities & Foundations; Community special interest groups; Biotechnology and pharmaceutical companies; Corporate organisations; Private health and medical device companies

Our Patron Sir Gustav Nossal opened the Awards and The Minister for Health, Greg Hunt gave the keynote address. Other key presenters included Chris Bowen MP, Frank McGuire, Prof Shitij Kapur (University of Melbourne), Professor Bonnie Barber, Griffith University, A/Prof Annette Schmiede, Bupa Health Foundation and Dr Andrew Weekes, GSK and of course Peter Wills AC.

**We congratulate all the winners and the highly commended finalists and wish them every success. Award Winners and the Award Presenters are below.**



The Peter Wills Medal  
Presented by Peter Wills AC  
**Professor Kathryn North AC**  
Murdoch Children's Research Institute



Frontiers Research Award  
Presented by Professor Shitij Kapur  
**A/Prof Jeremy Crook & Team**  
University of Wollongong



The Great Australian Philanthropy Award  
Presented by Sir Gustav Nossal AC CBE  
**Mrs Pamela Galli (accepted by Gayle Petty)**  
Trustee for the Lorenzo and Pamela Galli Charitable Trust

Griffith University Discovery Award  
Presented by Professor Bonnie Barber  
**Dr Christine Keenan**  
Walter & Eliza Hall Institute of Medical Research





# RESEARCH AUSTRALIA HEALTH & MEDICAL RESEARCH AWARDS 2019

The 17th Health and Medical Research Awards was held in Melbourne at Metropolis Southbank, Thursday 14 November. 280 people gathered for the black tie dinner and award ceremony.

This year UNSW Sydney sponsored the welcome cocktail reception and we had four Award Category Sponsors, GSK, Griffith, Bupa Health Foundation and the Victorian Government. Other sponsors included Monash University and Ingham Institute and we thank them for their invaluable support.

As per tradition the event convened an audience of influencers from across the sector including: Research organisations; Health providers; Peak bodies; Academic institutions; Charities & Foundations; Community special interest groups; Biotechnology and pharmaceutical companies; Corporate organisations; Private health and medical device companies

Our Patron Sir Gustav Nossal opened the Awards and The Minister for Health, Greg Hunt gave the keynote address. Other key presenters included Chris Bowen MP, Frank McGuire, Prof Shitij Kapur (University of Melbourne), Professor Bonnie Barber, Griffith University, A/Prof Annette Schmiede, Bupa Health Foundation and Dr Andrew Weekes, GSK and of course Peter Wills AC.

**We congratulate all the winners and the highly commended finalists and wish them every success. Award Winners and the Award Presenters are below.**



Advocacy Award  
Presented by The Hon Chris Bowen  
**Professor Gordon Lynch University of Melbourne**



Data Innovation Award  
Sponsored by Bupa Health Foundation  
**Professor John Lynch FAHMS (Accepted by Prof Andrew Zannettino)**  
**The University of Adelaide**



Health Services Research Award  
Sponsored by The Victorian Government  
**Professor Libby Roughead**  
**University of South Australia**



GSK Award for Research Excellence  
Presented by Dr Andrew Weekes  
**Professor Brendan Crabb AC**  
**The Burnet Institute**





## HEALTH SERVICES RESEARCH AWARD

Sponsored by The Victorian Government

### WINNER

Professor Libby Roughead



### HIGHLY COMMENDED

Prof Glenn Marshall AM FAHMS



## DATA INNOVATION AWARD

Sponsored by Bupa Health Foundation

### WINNER

Professor John Lynch FAHMS



### HIGHLY COMMENDED

LifeSpan data team  
(led by Matthew Phillips)



## ADVOCACY AWARD

### WINNER

Professor Gordon Lynch



### HIGHLY COMMENDED

Annabelle Wilson



Duncan McPherson  
OAM



## GRIFFITH UNIVERSITY DISCOVERY AWARD

### WINNER

Dr Christine Keenan



### HIGHLY COMMENDED

Dr Alexandra Bannach-Brown



## FRONTIERS RESEARCH AWARD

### WINNER

A/Prof Jeremy Crook & Team



### HIGHLY COMMENDED

Dr Lisa Gillinder



Professor Sailesh Kumar



**Research Australia congratulates all the Award winners and the Highly Commended finalists.**



# THANK YOU

On behalf of the Board and the Research Australia team, thank you to all nominators, finalists and attendees for supporting this important event.

Research Australia also extends its gratitude and appreciation to all the sponsors of this year's Health and Medical Research Awards, this event would not be possible without your valuable contribution.

## PREMIUM AWARD SPONSOR



## AWARD CATEGORY SPONSORS



## AWARD PARTNER



## EVENT SPONSOR



## Translating research into better health outcomes



*At Griffith University, our researchers are committed to developing healthy communities through exceptional health and medical research.*

We undertake research across the lifecycle to identify key factors that influence health. From this we develop and test strategies to improve health and wellbeing for individuals, families and communities.

Four overarching programs—Disability and Rehabilitation, the Economic, Policy and Innovation Centre for Health Systems (EPIC Health Systems), Healthcare Practice and Survivorship, and Infectious Diseases and Immunology—encapsulate our research strengths and align with local and national health priorities.

Discover more: [griffith.edu.au/menzies-institute](http://griffith.edu.au/menzies-institute)





## BUPA HEALTH FOUNDATION EMERGING HEALTH RESEARCHER AWARD 2019

**T**he Bupa Health Foundation Emerging Health Researcher Awards were launched in 2012 with the aim of supporting the health research leaders of the future, during the earlier stages of their career.

The 2019 finalists showcase the diversity of Australian health and medical research, working on public health, medical engineering, laboratory science and clinical research spanning fields including genetics, cancer and mental health.

Dr Myles Young, a Post-Doctoral Fellow at The University of Newcastle was announced as the 2019 winner for his work improving the physical and mental health of men.

"The programs are designed for men who want to lose a few kilos without necessarily having to hit the gym every morning or give up beer," explains Dr Myles Young. "The online nature of the programs is very important because it makes them confidential in nature, which a lot of men like. They are also easily accessible and teach men to make changes to improve their health in ways that are sustainable for a long time."

Myles hopes the award will continue to shine a spotlight on the significant issue of men's health and encourage more men to continually make positive changes to improve their physical and psychological wellbeing over the long term.

Since the award started eight years ago, the Bupa Health Foundation has invested \$374,000 to support Australia's emerging leaders in health research.

"Forging a career as a health and medical researcher can be challenging. Not only because of limited funding

for research, but also the dedication required to solve complex health problems which can take years to unravel," explains Annette Schmiede, Bupa Health Foundation Executive Leader. "The Bupa Health Foundation is proud to invest in Australian researchers as they navigate this critical career stage."

### 2019 AWARD RECIPIENTS

#### WINNER:

**Dr Myles Young**, Post-Doctoral Fellow, Priority Research Centre in Physical Activity and Nutrition, School of Education, University of Newcastle

Ares of focus: Innovative behavioural weight loss programs specifically designed for men and has co-developed a range of online 'gender-tailored' programs.

#### FINALISTS:

**Dr Jie Bin Lew**, Post-doctoral Research Fellow, Cancer Research Division, Cancer Council NSW.

**Dr Gemma Sharp**, NHMRC Early Career Research Fellow in the Monash Alfred Psychiatry Research Centre, Monash University

**Dr Saree Alnaghy**, Research Associate, Centre for Medical Radiation Physics, The University of Wollongong

**Dr Aideen McInerney-Leo**, NHMRC Research Fellow, Diamantina Institute, University of Queensland



The Bupa Health Foundation is one of Australia's leading corporate foundations dedicated to health. We partner with health and medical researchers to address the health needs of the Australian community and deliver on our purpose of helping people live longer, healthier, happier lives.

Our approach to partnering is to invest in research that improves health through changes to policy, practice and behaviour; collaborate with researchers across the academic, industry and healthcare sectors; advocate for those that are improving health; and to develop capabilities of the health and medical research community.

The Bupa Health Foundation was established in 2005 and has invested more than \$32million to support over 130 projects.



## Health Foundation



## Unparalleled research with global impact

We are investing in research excellence and world-class academics whose research has global impact.

UNSW Sydney Scientia Fellow Angelica Merlot is determined to outmanoeuvre some of the deadliest cancers. Named the youngest recipient of a National Health and Medical Research Council Grant, Angelica is working to develop new anti-cancer drugs that target drug resistance and suppress cancer spread.

From cancer research to mental health, infectious diseases and genomics, we are a world leader in biomedical sciences.

## 1st

First in Australia for Research Excellence and Impact – UNSW has more top ratings in broad fields of research (2018 ERA) and more impact cases rated high (2018 EI Assessment) than any other university in Australia.

## Top 43

UNSW is ranked one of the world's top research universities by QS.

## 7,000

UNSW has a 7,000 strong research community with more than 4,000 Higher Degree Research candidates.



# AUSTRALIAN RESEARCHER UNCOVERS KEYS TO MALARIA ELIMINATION.



**Professor Brendan Crabb AC, Director and CEO of the Burnet Institute has won the 2019 GSK Award for Research Excellence for his research into the DNA of the malaria parasite. His work has transformed how scientists explore malaria prevention and treatments globally.**

The GSK Award for Research Excellence is one of the most prestigious awards available to the Australian medical research community. It has been awarded since 1980 to recognise outstanding achievements in medical research with potential importance to human health.

Professor Crabb was involved in the technical breakthrough of DNA ‘transfection’ of the malaria parasite. Transfection is a powerful tool that enables scientists to manipulate the genome of the malaria parasite. By tweaking the parasite’s DNA, Prof Crabb is exploring which mutations are responsible for drug resistance and identifying parts of the parasite that can be targeted by new medicines and vaccines.

“Malaria is one of the most important health problems humans have ever faced. The scale is unimaginable with around 3.2 billion people at risk of the disease,” said Professor Crabb.

As malaria is a disease that effects the world’s poorest countries, Professor Crabb has focused the Burnet Institute’s resources on the health of neglected populations.

**“I’m so thrilled to win this award and to continue more research in an area that desperately needs it and to raise awareness of a disease that impacts people who are largely invisible, poor and marginalised. We need to draw attention to the fact that many of our human brothers and sisters are still suffering enormously from this disease,” he said.**

Benishar Kombut has worked alongside Professor Crabb at the Burnet flagship site in Papua New Guinea and is one of many there who have suffered at the hands of the parasite.

Benishar has had malaria multiple times since childhood. Most recently, her first child was diagnosed at just six weeks old. After he began sweating heavily and his eyes kept rolling back, the family rushed to a local clinic where



he was treated. If they had not sought medical attention so quickly, he might not have survived.

“The award provides a great opportunity to put the spotlight on the massive burden of malaria globally and encourage Australians to support researchers like Professor Crabb, whose work is having a huge impact around the world,” said Benishar.

Advancing research at all levels is critical as the malaria parasite has become resistant to a number of drugs that used to be effective in the past. Professor Crabb and his team have recently identified a molecular machine as a possible drug target. The \$80,000 prize that comes with the GSK Award for Research Excellence will be used to screen available drug compound libraries for a molecule that has an effect against this machine.

Dr Andrew Weekes, Medical Director of GSK Australia said GSK is proud to be supporting Australian researchers with this award, now in its 39th year.

**“The work of Professor Crabb is testament to the impact home-grown research and innovation can have on a global scale. We are honoured to recognise and support research that is making a major impact to human health. Brendan’s past and ongoing research has the potential to relieve the burden of malaria at scale, creating better outcomes for millions of people suffering from global health inequities,” said Mr Weekes.**

Among the previous recipients of the GSK Award for Research Excellence are some of Australia’s most noted scientific researchers, including Professor Tony Basten (1980), Professor Nicos Nicola (1993), and Professor Ingrid Scheffer (2013).

Professor Ingrid Scheffer reflects back on the impact that winning the GSK Award has had on her research and career.

“Receiving the honour of the GSK Award for Research Excellence signals that your work is at the cutting-edge of research both in Australia and internationally. It recognises those who are making a significant impact to human health, it is incredible to be recognised for making a real difference to people’s lives.”

Professor Scheffer, a paediatric neurologist and clinician-scientist at the University of Melbourne, Florey Institute and Murdoch Children’s Research Institutes, received the award for her work in improving diagnosis of childhood epilepsy. She believes that winning the award helped further energise her team to keep exploring this area of research. Since winning the award, they have made major strides in discovering underlying causes and working towards precision therapies for childhood epilepsy.

She was recently named president of the Australian Academy of Health and Medical Science (AAHMS). Professor Crabb is a Fellow of the AAHMS.

“Professor Crabb has shown great leadership in the Australian research community. The GSK Award for Research Excellence highlights the peak of Australian research, inspiring the entire local research community. At the AAHMS we are working to foster the next generation of health and medical researchers and Professor Crabb is a great role model,” said Professor Scheffer.

Professor Brendan Crabb received the GSK Award for Research Excellence at Research Australia’s 17th annual Health and Medical Research Awards in Melbourne.

**Author: GSK Australia**





# PUSHING THE ENVELOPE FOR THE SICKEST OF CHILDREN

The search for answers to rare diseases often results in diagnostic delays of months and even years; time that the sickest children in neonatal or paediatric intensive care may not have. But a transformative study led by the Murdoch Children's Research Institute is changing the diagnostic landscape.

**E**xponential advances in genomics research and technology are not only enabling scientists and clinicians to unravel the mystery behind rare diseases, but equipping them to do so faster than ever, resulting in life-changing answers for families.

Director of the Murdoch Children's Research Institute (MCRI), Professor Kathryn North AC, says that while individual inherited or genetic disorders may be rare – for example cystic fibrosis, muscular dystrophy, spinal muscular atrophy and Fragile X - collectively they are more common than people might realise.

“Combined together, so-called rare diseases affect at least one in 20 babies at birth, and account for 35 per cent of deaths in children aged under one year. Rare diseases are a major cause of major intellectual and physical disability and chronic disease burden.

At any one time 1 in 4 inpatients in a Children's Hospital have a “rare” disease as their primary diagnosis.

“In the past, we could give families with affected children a clinical description – a label - but we couldn't pinpoint the cause or define exactly what was wrong. So, only 10 per cent of patients had a diagnosis, and even then we couldn't offer any general treatments, much less any sort of precision therapy.

“Parents were desperately seeking an answer to the cause of their kids' intellectual or physical disability,





they wanted to know what to expect about their child's future, and whether there were risks to other family members or their future children. And what treatments could we offer. We just couldn't answer these questions," Professor North says.

And so the Acute Care Genomics study was born.

MCRI joined forces with hospitals, research centres and genetic pathology services across Victoria, NSW, Queensland and South Australia to push the envelope for the nation's sickest children.

The study, focused on implementing genomics into healthcare, was set up to provide ultra-rapid genomic testing for about 250 babies and children in intensive care units across Australia.

Research Director of Genomic Medicine at MCRI and Australian Genomics co-lead Professor John Christodoulou says the study harnessed the collaborative power of clinical and research genetics experts, together with a network of genetic curators, bioinformaticians and genetic counsellors who worked around the clock to find answers.

When we started this project two years ago, the gold standard for rapid diagnosis using genomic tests was, at best, four weeks, although it was more likely to take 4-6 months" Professor Christodoulou says.

**“ But we really wanted to take that a notch higher and see if we could deliver results to the sickest of children in under a week.”**

During the study, DNA samples were collected from infants and children at 18 neonatal and paediatric intensive care units in Australia and sent for rapid genomic analysis at MCRI's wholly owned subsidiary, Victorian Clinical Genetics Services (VCGS), or NSW Health Pathology in New South Wales.

At each stage of the process, from sample preparation and genomic sequencing, to computational analysis, diagnosis, results delivery and genetic counselling, teams at both centres worked to streamline processes and technological capabilities, returning diagnoses at a speed that was unprecedented in Australia.

By the end of its first year, the Acute Care Genomics study achieved its first milestone of providing rapid genomic testing to more than 100 critically ill children, delivering their results within days.

Professor North says, "I couldn't have imagined that we'd be using genomic technologies in the clinic within just two years of developing them in a research setting. We increased the diagnostic rate five-fold, and now

Philanthropic funding to the Murdoch Children's Research Institute acts as a seed, allowing us to develop early research work to a point where the researchers can apply for competitive grants.

Philanthropy, whether it be through bequests, workplace giving, competitive trust and foundation grants, community fundraising, corporate partnerships or the far-sighted generosity of major donors, makes a significant impact to change the face of child health now and for decades — perhaps centuries — to come.

have geneticists working side by side with intensive care physicians to provide a diagnosis within three days. It is without exaggeration an absolute game-changer, potentially giving families their children's lives back."

"Genomics happens in a space where collaboration is essential to delivery," says Professor North, who also leads the Australian Genomics network of genetics services, hospitals, universities, research institutions, and patient advocacy groups.

Australian Genomics is forging a nation-wide platform to establish procedures to enable all Australians equitable access to genomic healthcare.

Professor North is also Vice-Chair of the steering committee of the international advocacy and standards group Global Alliance for Genomics and Health. She leads the consortium of more than 500 institutions in more than 80 countries.

"Using global data gathered and shared responsibly from millions of people, we will be able to move to a healthcare model of prediction, prevention, early intervention and treatment, to eventually improve and maintain the wellness of the population, rather than focussing solely on illness," says Professor North.

"And while MCRI is at the forefront of genomics delivery, we couldn't find the answers without our invaluable national and international networks."

**Author: Tom Keeble BSc PhD, Communications Manager, Marketing and Communications Murdoch Children's Research Institute**



# THE ROLE OF PHILANTHROPY IN RARE DISEASE RESEARCH

In July 2019, two secret millionaires made headlines for leaving behind the largest bequest in the Australian National University's history. CEO of Rare Voices Australia, Nicole Millis, considers philanthropy's role in rare disease research moving forward.

**W**hen my son was first diagnosed with a rare disease eighteen years ago, I found myself having similar conversations with well-meaning friends. It went something like this:

Them: "What disease is it? I haven't heard of that... how do they fix it? What is the treatment?"

Me: "The symptoms can be eased but there is no treatment for the underlying cause."

Them: "No treatment? Really? Well, don't worry. Medical breakthroughs are taking place each day... there will be something just around the corner!"

For many people living with rare disease, too often, there isn't 'something' just around the corner. For many rare diseases, no research is taking place in Australia or anywhere in the world. A disease is considered rare if it affects less than five in 10,000 people and there are around 7,000 different rare diseases. While individual diseases may be rare, the total number of Australians living with rare disease — an estimated two million Australians — is not. Around 80% of rare diseases are genetic and sadly, too many babies born with rare disease never reach adulthood.

## RARE DISEASE RESEARCH: THE CHALLENGES

For many rare diseases, there are a number of barriers to effective research and no active research programs. Rare diseases have small numbers and are often very complex. Historically, individual rare diseases have had little attention from government research funders, while researchers face an uphill battle in securing funding and coordinating statistically robust studies. Pharmaceutical industry interest in rare disease research and development

can be minimal due to relatively low demand.

Depending on the specific rare disease, research priorities can be quite different. While funding for translational research may be important for many rare diseases, some rare diseases are not yet in the position to prioritise this type of research. Instead, for some rare diseases, the unmet research needs are basic discovery research or investment into data collection and natural history studies.

People living with rare disease need investment into all types of research. Additionally, for many, participation in a clinical trial may be the only way to access treatment. A 2016 Australian study by Molster et al (see footnote below) found that almost 90% of respondents living with rare disease were interested in joining a registry, in recognition of the key role registries play in linking people living with rare disease with clinical trials for new health technologies (drug treatments and therapies).

Molster, C., Urwin, D., Di Pietro, L. et al. Survey of healthcare experiences of Australian adults living with rare diseases. *Orphanet J Rare Dis* 11, 30 (2016) doi:10.1186/s13023-016-0409-z

Time is critical in rare disease; research must be innovative, address existing gaps and the coordination of rare disease research projects must be prioritised. Rare Voices Australia understands that Australia needs to foster, support and drive all types of rare disease research and that this approach needs to be collaborative and person-centred.

## PHILANTHROPY AND RARE DISEASE RESEARCH

There is a clear role for philanthropy in rare disease research where funds and people power can make a

real difference. There are also many complexities at play. Perhaps more pertinent questions are who should drive this philanthropy and how?

"But if we (people living with rare disease) don't do it, who will?" says Megan Donnell, founder of RVA Partner organisation, Sanfilippo Children's Foundation.

Most rare disease organisations have a goal to promote or support research for their specific rare disease. Fundraising gives a much-needed feeling of empowerment but such work must be balanced against the existing burden on families. Rare disease is progressive and life limiting and families often don't have the time to fundraise. We know support organisations are under-resourced, are largely volunteer-based and can have limited ability to raise funds, posing a risk to their long-term sustainability. Some organisations report great difficulty in simply applying for available funding.

"In Australia, we have found it really hard to fit into any of the grants because our needs are unique, which most rare diseases are so we have been unsuccessful on almost every philanthropic grant we have applied for," says one RVA Partner organisation leader.

In reality, the issues with philanthropy and rare disease research run deeper than simply funding, extending to a myriad of factors such as insufficient resourcing, difficulty meeting research goals and so on.

## RARE DISEASE RESEARCH FUNDING CANNOT DERIVE SOLELY FROM PHILANTHROPY

Raising funds for rare diseases with low awareness levels and small numbers is difficult. Increasingly, the NGO sector is playing a vital 'linking' role in philanthropy

Nicole Millis, CEO of Rare Voices Australia (RVA), speaking at a recent RVA Parliamentary Event.



between funders, researchers and ideas. Everyone knows a family touched by cancer; the same cannot be said for most rare diseases. That personal connection people have with a cause is often lacking in rare disease.

Philanthropy is important but it is only one source of funding, alongside Commonwealth and state and territory government funding, and private sector investment. Arguably, to increase the impact of philanthropy, rare disease organisations will increasingly need to consider working more collaboratively (eg. across similar disease areas) and potentially, explore new models (eg. venture philanthropy).

Fundraising can empower people living with rare disease and provide them with a way to be part of a potential solution. The soon-to-be launched National Strategic Action Plan for Rare Diseases calls for the development of a sustainable rare disease research strategy to guide the all-important work being conducted in the rare disease research space.

**Author: Nicole Millis is Rare Voices Australia's Chief Executive Officer.** A qualified social worker with a background in families, disability and program management; and previously the National Manager of MPS & Related Diseases Society Australia, Nicole has both personal and professional experience of the rare disease sector. She has significant experience in rare disease advocacy, particularly in access to treatments. Nicole has recently been appointed as the consumer nominee on the Life Saving Drugs Program Expert Panel.



# THE KIDS' CANCER PROJECT

SUPPORTING  
CHILDHOOD  
CANCER  
RESEARCH  
SINCE 1993.

Back in the late 1980s, Col Reynolds had a life changing experience.

Little did he know that a pair of bald kids crossing in front of the tourist coach he was driving outside the Children's Hospital in Camperdown, New South Wales, would have him taking the ride of his life. On a whim, he pulled over and followed them in.

Desperate to give those children and their families something he had plenty of, he gave them the gift of freedom on bus trips to beaches, gardens and amusement parks only to realise those little escapes were not a panacea.

He eventually made the discovery that for all the smiles, hugs and visits to ice cream parlours, the only way to improve outcomes for these kids would be through sheer hard work in the lab and for him to step out of his comfort zone. That was then. Today, the organisation he founded in 1993 - The Kids' Cancer Project - has saved countless lives by ensuring scientists receive the funding they need.

## HOW TKCP HAS GROWN

Twenty-six years ago, Col was able to fund a single scientific study from the proceeds of raffle tickets he sold from his local supermarket carpark. He was one man making a difference, but with the power of the entire community behind him the charity grew exponentially.

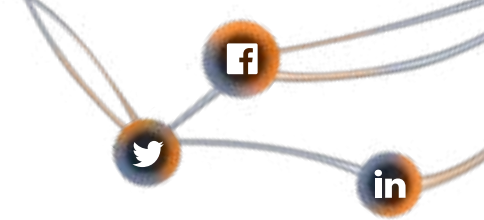
"Our commitment to science resonates with anyone who has been touched by this insidious disease," said Col who received an OAM in 2000 in recognition of his determination to make a difference to the lives of children diagnosed with cancer.

**“Those families have become part of our family and together with the generosity of others who believe science is the solution, we are making inroads to discovery,” he said.**

In 2012, the charity had come of age. In that year alone it committed almost \$2.8 million to fund 15 separate scientific studies around the country to find better treatments and a cure for childhood cancer.

Currently, The Kids' Cancer Project is funding 35 projects across 22 institutes covering every state in Australia with proceeds from a strategically balanced fundraising model.





## THE KIDS' CANCER PROJECT RESEARCH ADVISORY COMMITTEE\*

- Associate Professor David Ziegler, MBBS UNSW, MD/PhD UNSW, Dip Paed, FRACP, Chair  
Paediatric Oncologist with expertise in neuro-oncology and early phase clinical trials
- Dr Justine Stehn, PhD  
Research scientist with academic and industry experience in translational cancer research
- Dr Andrew Moore MBBS, FRACP, PhD  
Paediatric Oncologist and Director of the Queensland Children's Tumour Bank
- Professor Jonathan G Izant, PhD  
International experience in biomedical research, business and non-profit leadership
- Professor Murray Norris, AM BSc ANU, MAppSc NSWIT, PhD UNSW  
Awarded scientist who has dedicated 30 years of his life to kids' cancer research
- Dr Brenda Weigel, MD, MSc  
Director, Division of Pediatric Haematology/Oncology, University of Minnesota
- Dr Timothy P Cripe, MD, PhD  
Division Chief, Pediatric Hematology, Oncology and BMT, Nationwide Children's Hospital, Ohio

\*The rules of the peer review process strictly state that RAC members cannot review and make recommendations on their own projects.

## EXPERT RESEARCH ADVISORY COMMITTEE

Engaging the community to raise capital to inject into medical research is an artform that Col and his team have perfected, but he's happy to leave the grant selection process to a seasoned panel of industry experts.

The Kids' Cancer Project has a Research Advisory Committee (RAC) at their disposal to independently review all submissions and score them against nine key requirements. Each submission must detail the aim of the planned study specifying how it will assist in finding cures for childhood cancer.

The RAC meet to discuss their individual scores before presenting a unified recommendation to the Board who make the final decision based on that presentation.

## SCIENCE. SOLUTIONS. SURVIVAL.

For Dr Diane Hanna, paediatric oncologist at Melbourne's Royal Children's Hospital and researcher at the Walter and Eliza Hall Institute of Medical Research, funding came at a critical time.

Dr Hanna's research is looking at particular sub-types of acute lymphoblastic leukaemia (ALL) that are resistant to conventional chemotherapy, accounting for up to half of adolescent and young adult (AYA) patients.

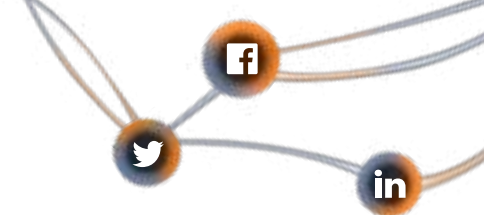
With funding, Dr Hanna has been able to test a novel drug class in the lab to identify treatment combinations that show the greatest effect on killing cancer cells. Ultimately, her aim is to progress the research to clinical trials in the hope of improving cure rates.

She says her work is looking very promising. "I've set up toxicity assays in the laboratory to ensure that the combination of molecules is tolerable without significant side effects and I've been able to determine the maximum tolerated dose," says Dr Hanna.

"This is the year where I'm able to tie up all the loose ends and move forward with answering some critical questions that will be helpful in developing early phase trials in the clinic," she says.



# PHILANTHROPY & GOVERNMENT PARTNER FOR PATIENT SELF- MANAGEMENT PROGRAM



Heart disease is a growing public health threat. Up to 90% of the overall risk of acute myocardial infarction (AMI) is attributed to modifiable factors including medication non-adherence, cigarette smoking, poor diet, physical inactivity and negative mood states such as anxiety and depression. Patients who have had a cardiac event are at increased risk of a subsequent event and death.

**W**hile cardiac rehabilitation (CR) is recommended for all patients after an acute cardiac event and has been shown to improve survival<sup>1</sup>, there is a need for flexible alternatives to traditional centre-based CR.

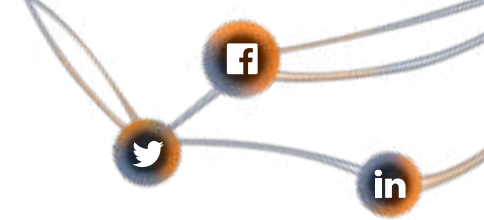
“Traditional CR focuses on physical reconditioning and information provision to assist patients to return to usual activities and initiate required behaviour changes, but few programs in Australia provide patients with the behavioural and cognitive skills for long-term self-management.

Moreover, few programs adequately address the management of negative emotions such as anxiety, depression and anger”, explains Dr Barbara Murphy, Principal Researcher at the Australian Centre for Heart Health (ACHH). In addition, up to 70% of eligible patients do not attend centre-based CR, many patients preferring or requiring home-based models of learning incorporating e-health delivery options<sup>2</sup>.

The ACHH has developed a suite of three programs – the Beating Heart Problems program (face-to-face group-based with a trained health professional), Teleheart (telephone delivered, one-on-one with a trained health professional), and Back on Track (online, home-based, individual) – to assist cardiac patients in the management of their disease, and in the prevention of secondary cardiac events.

According to Associate Professor Rosemary Higgins, Health Psychologist at the ACHH, “All three programs are based on the principles of cognitive behaviour therapy and motivational interviewing, and all incorporate self-monitoring strategies to enhance their effectiveness in long-term patient self-management of behavioural and emotional health after an acute cardiac event”.





The development and trialling of these programs would not have been possible without considerable philanthropic and government support.

#### DEVELOPMENT OF THE ‘BEATING HEART PROBLEMS’ PROGRAM

With funding from Australian Rotary Health and the Norman H. Johns Trust, the Centre developed the 8-week centre-based Beating Heart Problems program. The program is group-based and facilitated by a health psychologist and cardiac nurse. The program addresses four key health behaviours – healthy eating, physical activity, smoking cessation and medication adherence – and four key psychosocial issues – managing depression, anxiety and anger, and increasing social support. Each session incorporates goal setting, self-monitoring, homework tasks, role modelling, and relapse prevention strategies.

“*In a 4-year randomised controlled trial, which commenced in 2008 and involved 275 patients from the Royal Melbourne and Melbourne Private Hospitals, we demonstrated that the Beating Heart Problems program significantly reduced patients’ cardiac risk, and improved their health behaviours and mental health.<sup>3,4</sup> Like the development of the program, the trial was funded by Australian Rotary Health and the Norman H. Johns Trust.*

#### DEVELOPMENT OF THE TELEHEART PROGRAM

With funding from the Victorian Cardiac Clinical Network (VCCN), we developed and piloted the ‘Teleheart’ telephone-delivered self-management program to extend the reach of secondary prevention care provided in the group-based Beating Heart Problems program. The program is delivered by a health psychologist by telephone, with individual sessions lasting up to one hour each. Teleheart begins with a mandatory goal-setting module, followed by a suite of self-selected modules relating to dietary change; physical activity and reduced sitting; smoking cessation; and management of anxiety and depression.

The pilot study, involving 22 cardiac patients from Monash Health during 2015-16, demonstrated that the program was acceptable to patients and improved their self-management of their health behaviours and emotional wellbeing<sup>5</sup>.

#### DEVELOPMENT OF BACK ON TRACK ONLINE PROGRAM

With funding from the HCF Research Foundation, we simultaneously developed and piloted the ‘Back on Track’

online self-management program to further extend the reach of the original group program. Current estimates suggest that 88% of Australian adults are active internet users and that 84% of users, including those of older ages, access health-related information. Back on Track, which was developed using a co-design approach involving patients themselves, includes modules on goal-setting, dietary change; physical activity; smoking cessation; and management of anxiety and depression.

The pilot study, undertaken with 23 cardiac patients from Cabrini Health during 2015-2016, demonstrated the program’s acceptability as a means of self-management support<sup>6</sup>.

Finally, to build on their initial investment, we recently received a second grant from the HCF Research Foundation to test two methods of delivery of the Back on Track program – one self-directed by the patient, and one supported by telephone sessions with a health psychologist. Outcomes for the two groups will be compared post-program and 4 months later to determine immediate and sustained benefits of the two approaches. Trialling of the two methods of delivery will begin in 2020 and continue for two years, involving up to 300 patients.

“This 10-year project, which has resulted in three evidence-based programs for self-management of behavioural and mental health, would not have been possible without the support from both philanthropy and government”, noted Professor Alun Jackson, ACHH Director.

**Authors: Dr Barbara Murphy**, Principal Researcher. **Associate Professor Rosemary Higgins**, Clinical Consultant. **Professor Alun Jackson**, Director. **Australian Centre for Heart Health**

1. Beauchamp A, Worcester M, Ng A, Murphy B, et al. Attendance at cardiac rehabilitation is associated with lower all-cause mortality after 14 years of follow-up. *Heart* 2013; 99: 620-625.
2. Higgins RO, Murphy BM, Le Grande MR, et al. Expressed preferences for health education of patients after percutaneous coronary intervention. *Eur J Cardiovasc Prev Rehabil* 2005; 12: 572-579.
3. Murphy BM, Worcester MUC, Higgins RO, et al. Reduction in two-year recurrent risk score and improved behavioural outcomes after participation in the Beating Heart Problems self-management program: results of a randomised controlled trial. *J Cardiopulm Rehabil Prev* 2013; 33: 220-228.
4. Turner A, Murphy B, Higgins R, et al. An integrated secondary prevention group program reduces depression in cardiac patients. *Eur J Prev Cardiol* 2014; 21: 153-162.
5. Higgins RO, Murphy BM, Navaratnam H, et al. Extending cardiac rehabilitation: a telephone self-regulation pilot. *Brit J Cardiac Nurs* 2017; 12: 398-406.
6. Higgins RO, Rogerson M, Murphy BM, et al. Cardiac rehabilitation online pilot: extending reach of cardiac rehabilitation. *J Cardiovasc Nurs* 2017; 32 7-13.



# #QUITGIVINGDAY IMAGINE WHAT'S NEXT

## MAKING IT REAL AND PERSONAL

### How cancer research benefited from the generosity of the QUT community

**R**eal-world applications for QUT research helped bring urgency and relevance to a fundraising campaign in May that involved 2029 donors, more than 300 ambassadors and 22 university projects.

Crowdfunding to unlock big challenge gifts was a major drawcard for QUT Giving Day, an innovative way to engage broad communities in fundraising for university projects that included medical and environmental research.

Particularly successful was cancer researcher Associate Professor Chamindie Punyadeera's fundraising, in memory of Jake Simpson, who died from head and neck cancer at the age of 23.

His family supported the campaign, bringing Associate Professor Punyadeera a step closer to translating her research into better testing for early cancer detection.

Mr Simpson's \$20,000 donation, which was given through the RBWH Foundation for early detection of head and neck cancer, kicked off the research team's QUT Giving Day campaign with a challenge that inspired others to give.

QUT Giving Day took Associate Professor Punyadeera's team out of the laboratories at QUT's Institute of Health and Biomedical Innovation (IHBI) and the School of Biomedical Sciences to communicate their research to the general public.

The team produced videos for social media channels, sent emails and spoke to members of the public at QUT's campuses. Mr Simpson's partner Carly Mulheran was a driving force to help get the word out and became the top QUT Giving Day ambassador.

Research team member and Peter Doherty NHMRC Early Career Fellow Dr Arutha Kulasinghe says the day provided an opportunity to showcase research and appreciate the importance of engaging with the broader community to explain research translation.

"We were able to engage with members of the public and discuss how our research may have translational potential – ultimately benefitting them," he says.

"Simplifying our research into small palatable chunks of information can be challenging. Giving Day challenged us to communicate our research with less scientific jargon."

Working with QUT's Media team, Associate Professor Punyadeera and her team's clinical collaborator Professor Liz Kenny AO, a Senior Radiation Oncologist at the Royal Brisbane and Women's Hospital, secured coverage on Australia-wide television news.

Importantly, the news coverage reflected on the importance of head and neck cancer research through a focus on people's lives and highlighting the importance of early detection.

Featured as part of the coverage was Ms Mulheran, sharing that it was only eight months from the time of diagnosis to Mr Simpson's untimely death.

Associate Professor Punyadeera's research recognises that head and neck cancers are often diagnosed at an aggressive stage, when the patient prognosis is poor, with a five-year survival rate of 50 per cent.

Her team is developing a technology that can detect biomolecules in saliva and blood that show cancer activity. The technology also has the potential to diagnose head and neck cancer at an early stage.

"We develop lab-based biomarker technologies for the early detection of individuals at a high risk of developing

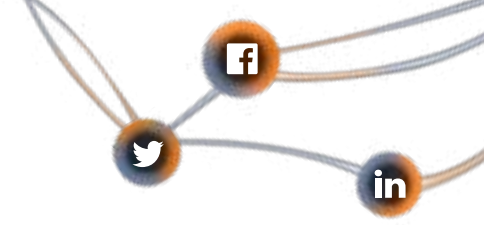


head and neck cancers," Associate Professor Punyadeera says. "We also are developing tools to monitor a patient's response to treatment."

Researchers aim to identify the biomolecules and proteins specific for cancers and heart disease, providing the validation needed to move the technology from the laboratory towards use in the real world.

Saliva and blood samples are collected from patients at the partner institutions, the Princess Alexandra Hospital,





- QUT's second annual Giving Day raised \$813,681 from 2029 donors for 22 university projects.
- The day builds on a solid foundation of philanthropy at QUT, which has an active Staff Giving program and strong alumni engagement.
- It encouraged a culture of philanthropy across the entire university community, involving students, academics, alumni, corporates and research partners.
- It is part of a program of engagement activity, rather than a stand-alone event.
- QUT Giving Day attracted donors from across Australia and the world.

the Mater Outpatient Clinic and the Royal Brisbane and Women's Hospital, with the aim of developing non-invasive diagnostics to detect disease early.

**“The aim is to ultimately secure funding for a clinical trial and prove the efficacy of using saliva. We believe saliva is the way forward in diagnostics. Saliva mirrors the body's health and wellbeing.”**

Associate Professor Punyadeera also has a personal motivation for pursuing the research. Her mother has been diagnosed with type 2 diabetes and her brother-in-law has died of head and neck cancer.

“I have seen how diagnosing cancer at an advanced stage can impact on a family,” she says. “Early detection is key to minimising the impact. Our research is all about picking up the early changes in the mouth that show up in saliva. Hopefully we can save lives.”

Seven campaigns highlighted IHBI research and secured more than \$77,000 in support from alumni, corporate donors, philanthropists, new donors and QUT staff.

The support enabled the roll-out of *IHBI Innovation Ideas Grants* to fund pilot studies and other research purposes for which alternative financial support may not be readily available.

Funding will also help develop new therapeutics and treatments for prostate cancer; build an evidence base for using new technology to monitor breast density; and to investigate genetic coding linked to cancer development.

Other research is taking inspiration from dragonfly wings to investigate nanotextured surfaces that kill pathogens on contact and address high rates of hospital-acquired infections; and using collaboration with GPs and practice nurses to improve the care and outcomes of cancer survivors.

“Our involvement in QUT Giving Day is all about supporting research and development to speed up translation of research from my laboratory to the community,” Associate Professor Punyadeera says. “Ultimately, it's about improving health for all Australians and saving the lives of people such as Jake.”

**Author: Erik de Wit**, Communications Program Coordinator, Institute of Health and Biomedical Innovation, QUT



# UNDERSTANDING AND COMMUNICATING RESEARCH IMPACT

In 2014 I saw a global shift toward identifying and communicating research impact.

**D**riven to reimagine the possibilities and revolutionise knowledge sharing to create a better world I stepped outside of the walls of a single institution so that I could advocate for, and help, a broader global audience.

This was the beginning of my consultancy, the Research Impact Academy. Since then I have been providing training on knowledge translation, otherwise known as impact pathways, and on research impact; to build the capacity of researchers and research support staff in Australia, New Zealand and several other countries.

In Australia, research impact skills and knowledge have become increasingly important for a number of reasons. Firstly, at the core of every researcher, there is a drive to discover new things. Some of these are going to directly change a process or practice within society,

others may guide conversations and thinking, whilst the fundamental research will shape what we know and drive future research directions that ultimately result in impact. It is important to remember that even applied research often stems from a fundamental research focus. Second, impact is becoming increasingly relevant due to the focus of research funding bodies the impacts or return on investment of research funding.

In 2018, the National Health and Medical Research Council (NHMRC) rolled out its new grant scheme, including the Investigator Grants. These grants, in an Australian first, required an Impact Case Study to be submitted as part of the applicant's track record component of the application. This change led to us working with over 160 researchers across health and medicine disciplines from more than 20 universities and institutes in Australia, to review and

refine their impact case studies. Through this process, we witnessed many different approaches and heard firsthand the misunderstandings and frustrations from the researcher's perspective.

This experience demonstrated not only shortcomings with the application process and guidance, but a more general lack of understanding in the research sector about what impact is and how it can be created, captured, and communicated. This is no surprise, and it is something I have seen many times with the thousands of researchers I have worked with. It was this opportunity to help others gain these valuable insights and skills that inspired me to take the path I have.

## COMMON MISTAKES AND MISUNDERSTANDINGS

The NHMRC impact case study, required applicants to write about the real-world impact from a past program of work in three sections of 2000 characters each:

1. **Reach and significance of the research impact;**
2. **Research program's contribution to the research impact; and**
3. **Applicant's contribution to the research program.**

Each of these sections posed their own problems and are indicative of the confusing and ambiguous terminology used within the guidelines. This led to consternation among many applicants as to what should go into each of three sections, due to inexperience in understanding impact, and limited best practice examples. A constant for us was the need to map out the fundamentals of an impact pathway before we could begin to communicate the resultant use of the researcher's evidence. Not surprisingly, these fundamental gaps were particularly apparent in researchers from the basic sciences.

**“Researchers often misunderstand the meaning of impact, mistaking the outcomes of their research project or study for the impact, rather than use of the knowledge or sharing of an output from that study that leads to a change.**

This misunderstanding led to researchers wanting to write about the latest research that they did or their prospective and newly funded research, when it is well established that impact takes time, and they are more likely to be able to demonstrate impact with their earlier research.

## REVIEWER PERSPECTIVES

Not only did I work with applicants but I also had many conversations with reviewers undertaking the assessment of applications about the process and the areas they struggled with. These discussions highlighted many of the

same issues in understanding both the fundamentals of impact and deciphering ambiguous terminology.

There appeared to be wide disparity in the expectations of reviewers based on their individual interpretations of the guidance documents. Additionally, there was a reviewer expectation that those applying for the leadership levels, due to their seniority, should have multiple if not all impact types listed, suggesting that the more types of impact, the better the researcher. This is problematic as not all types of research will generate multiple types of impact, particularly for basic scientists.

## Some advice for applicants

The following is my advice to prospective applicants for Investigator grants.

Read and use the following key elements from the guidelines:

1. Understand what is meant by a program of work. The definition clearly states that this is a cohesive body of research by the applicant.
2. The definition of impact includes three key terms that are helpful in articulating the programs impact. Use these terms: adopted, adapted, or used, where appropriate.
3. Use the category descriptor tables that outline expectations across the different impact types.

Overall, it was an absolute pleasure and privilege to work with so many talented researchers across Australia and to learn about the amazing impacts of their work. As a nation, we should be incredibly proud of the depth, breath and reach of our health and medical research contributions to society, I sure am. I just wish we were better at communicating these to each other and to the rest of Australia!

**Author: Tamika Heiden** is the Founder and Principal of the Research Impact Academy, a service that facilitates the creation, capture and communication of impact. She works with researchers to ensure their work is relevant, recognised and that it provides benefit and value to the next user.  
**Knowledge Translation Australia**





# COMMUNICATING IMPACT TO DONORS

**“It is not difficult to simply give away money, but it is challenging to do it effectively.” – Equity Trustees**

**M**ater Research is a leading medical research institute, located in Brisbane. Its focus includes mother and baby health, cancer biology, neuroscience and chronic disease research.

For these researchers, philanthropy keeps the wheels turning. Philanthropy is a key resource for research funding and at Mater Research philanthropic funding now counts for about 40% of the annual budget.

A clear trend is emerging among donors giving to research: they increasingly want to be better informed and more engaged in their giving. Donors, particularly those offering larger gifts, are looking to closely track the impact their investment in research is having.

Some donors are interacting with charities in entirely new ways, from emerging programs in impact investment and philanthro-capitalism (donors who get actively involved in managing their donations like a business) to large funding bodies with specific goals such as increasing gender equity or supporting early career researchers, through to individual donors who have interests in specific areas due to personal experience.

The consistent factor among these groups is an interest in mapping and measuring the impact their research gifts are having.

This presents an increasing challenge for fundraisers and researchers in keeping donors informed about the impact of their donations, and the twists and turns that research projects can take as they progress along the translational pipeline.

As well as publications, citations, patents and the traditional impact measures tracked by researchers, there is a demand for examples of outcomes for the community, narratives that can be shared by networks and examples of institutional change such as measureable increases in gender equity.

**“ This is further complicated by the nature of philanthropic funding for research. No single gift can solve a problem as large as a health issue.**

For example, in 2003 Mater Foundation received a \$1 million gift to fund prostate cancer research. Since then numerous donors and organisations have partnered with Mater to fund prostate cancer research, and despite major improvements in treatment and diagnosis, more than 21,000 Australian men will be diagnosed with prostate cancer this year, and more than 3000 will die.

In order for donors to make a research impact, they often have to be part of a larger group. Medical research is an expensive undertaking, with extended timeframes, and no guarantee of success.

Individual projects or researchers can be funded by a variety of philanthropic sources, with differing expectations of success and impact.

And despite this increasing connection between donors and research, researchers rarely receive training to help them communicate their work to audiences outside their peers.

This is a real problem: articulating science in lay terms helps researchers better connect with donors and with other audiences, and in doing so, can help their research and career.

To overcome these challenges Mater has launched a comprehensive suite of programs aimed at upskilling researchers, fundraisers, and marketing and communication staff to articulate the successes, challenges and impacts of research undertaken at Mater.

The first of these programs, the Bridge program, utilises the talents of science communicators and philanthropic engagement experts to engage, mentor and upskill researchers in presenting to lay audiences and engaging with the general public, particularly consumers and donors.

## THE GOALS OF THE PROGRAM INCLUDE:

- Assisting researchers in creating awareness about their research among the general public, particularly donors, to help broaden the impact of their research.
- Increasing researchers' opportunities to attract funding from donors.
- Helping retain donors over time, as donors are more engaged and understand their unique role in research progression.

These skills are particularly important for researchers interacting with philanthro-capitalists, and major donors interested in specific research areas. For these donors, researchers need to develop a clearly understood story with measurable milestones to demonstrate progress

toward developing a treatment for the condition of interest.

A second Mater program, the Immersion Program, aims to empower fundraisers, and marketing and communications teams, to communicate the research and clinical work underway at Mater. These teams are key conduits between Mater and its supporters and it is imperative that they understand, and feel confident in communicating, the work of Mater's researchers and clinicians.

The program is a deep dive into how Mater's researchers, clinicians and educators collaborate to treat and improve current health needs.

Through the presentations of researchers and clinicians upskilled in the Bridge program, the Immersion Program assists attendees to understand the translational bench to bedside methodology and the linkages between the work of Mater Research and the impact that it has on patient care and communication in a clinical setting.

While these programs are still new, Mater has already seen improvement in how we communicate with donors. And by increasingly engaging with researchers directly, donors understand more clearly where their donations are going and the impact they are having.

**Author: Shannon Ryan** is a Philanthropic Engagement Manager at Mater. He plays a key role liaising between Mater Research and the philanthropic ministry Mater Foundation.



# HEALTHY LESSONS FOR THE NEXT GENERATION

Each week, 73-year-old Emeritus Professor Tian Po Oei and his wife Elizabeth attend health and wellbeing sessions at UQ Healthy Living. University of Queensland students from a range of health courses design health sessions and chronic disease prevention programs in consultation with leading UQ academics.



**A**fter more than 40 years of teaching psychology students at The University of Queensland, Emeritus Professor Tian Po Oei continues to contribute to student learning by attending sessions at UQ Healthy Living. Professor Oei is among the over-50s community at UQ Healthy Living who have prioritised healthy active ageing for longevity and wellbeing.

"I feel it is my good fortune that by taking care of my health and wellbeing in retirement, I can also contribute to the learning and training of UQ students," Professor Oei said.

"We are really happy with the facilities and the students are always very helpful and enthusiastic in helping to guide our exercises. By maintaining our fitness and wellbeing, we can carry out our routines of living peacefully."

The first of its kind, UQ Healthy Living offers health and wellbeing services including counselling, psychology, occupational therapy and physiotherapy. There are also chronic disease management programs available for clients including those with osteoporosis, diabetes and Parkinson's.

The range of services offered enables a model that is underpinned by interprofessional collaboration in

education and practice. Interprofessional education occurs when individuals in two or more professions learn about, from, and with each other to enable effective collaboration that improves health outcomes and supports a model of collaborative practice.

UQ Faculty of Health and Behavioural Sciences Executive Dean Professor Bruce Abernethy said UQ Healthy Living provides students with the opportunity to understand the significance of interprofessional practice and the expertise that each discipline brings to improve health outcomes.

**“Students work with a range of clients from different backgrounds, who have varying health issues. These experiences challenge them to be innovative, utilise their clinical reasoning skills and equip them to be work-ready graduates in a complex healthcare environment,” Professor Abernethy said.**

UQ Healthy Living is managed by UQ Health Care, a not-for-profit company 100 per cent owned by UQ. UQ Health Care Chief Executive Officer, Darryl Grundy said

the intergenerational aspect is highly valued by both the over-50s and the students.

"Clients have shared feedback about their positive interactions with students and the level of support they received," Mr Grundy said.

"It's an experience for the students that's both enjoyable and educational, while the older generations experience social and emotional benefits from dealing with the younger generation in this setting."

Facilitating social connections is also integral to healthy ageing and therefore a key element for UQ Healthy Living.

"It's great to see clients enjoying their exercise together, learning more about their health, working together to problem solve their health issues, and forming friendships outside of the clinic," Mr Grundy said.

"I love that the clients come here motivated to change their health and make positive changes to their lifestyles. This positive attitude inspires others around them, as well as the student practitioners."

UQ Healthy Living facilitates the translation of the latest research on cognitive, physical, mental and social wellbeing to be implemented into practice. UQ Healthy

Living Manager David Da Silva said UQ provides access to some of the highest calibre of researchers, teachers and scholars focussed on ageing research across a wide range of disciplines.

"These collaborative opportunities provide value for both clients and students, as well as enabling us to push the boundaries of best practice and to grow in exciting ways," Mr Da Silva said.

"Recently, UQ's Professor Nancy Pachana, an expert in geriatric mental health presented to clients about the health benefits of human-animal interactions. Professor Pachana discussed how interacting with animals has proved to lower cortisol levels and blood pressure, reduce loneliness and sharpen your mind."

UQ Healthy Living is paving the way as a leader in developing and supporting clinical services, creating a best practice model of health care for the healthy ageing population, and facilitating authentic interprofessional education and practice opportunities for students.

**Author: University of Queensland**



## ALCOHOL HOME DELIVERY SERVICES

# AN INVESTIGATION OF USE AND RISK

The Foundation for Alcohol Research and Education (FARE) and research partner, the Centre for Alcohol Policy Research (CAPR) at La Trobe University, have published a study looking at how people are using alcohol home delivery services. Online sales and delivery services operate in an uncertain regulatory environment and there has been little research into their use in Australia.

Online sale and delivery services account for a growing share of the alcohol market in Australia, driven by a mix of existing retailers shifting into the online space and new players. An IBIS World market research report on online alcohol sales in Australia estimates that around five per cent of all alcohol is currently sold via online channels, with growth forecast at more than 10 per cent per year over the next five years. Between 2014 and 2018, online sales and revenue each grew by around 14 per cent per year.

The results of two population surveys in 2013 and 2018 also suggest substantial growth. In 2013, just four per

cent of Australians reported using phone/email/internet to purchase takeaway alcohol in the past six months, rising to 33 per cent by 2019. In 2019, one in eight Australians (13 per cent) who have used an alcohol delivery service reported using this service at least fortnightly.

The CAPR report *Alcohol home delivery services: An investigation of use and risk* was based on a survey of 528 participants aged 18 to 69 who used an online alcohol delivery service in the past month. Although not a representative population sample, this study provides the first detailed information on people who order alcohol online in Australia.

The study by Yvette Mojica-Perez, Dr Sarah Callinan and Dr Michael Livingston indicates that while a wide range of people use online alcohol delivery services, rapid delivery services (< 2 hours) were most popular among the youngest age group of 18 to 29-year-olds.

One in five participants (22 per cent) who ordered alcohol via a rapid delivery service did so because they were over the blood alcohol limit to drive. Meanwhile, more than a quarter of participants who used rapid services (28 per cent) reported that the delivery enabled them to continue drinking when they would otherwise have had to stop.

Participants who received their most recent order within two hours were categorised as ordering from a rapid (or 'on-demand') delivery service provided by both bottleshops and specialised fast delivery services.

The CAPR study also highlights the brand prominence and market strength of established players, notably Woolworths. Around half of all respondents receiving rapid deliveries had ordered from traditional liquor outlets, such as Woolworths-owned brands Dan Murphy's and BWS that offer specific rapid services, while the other half ordered from specialised and newer fast delivery services like Jimmy Brings (also owned by Woolworths) and Tipple, which describes itself as 'a bottle shop in your pocket'.

There are several other concerning findings. The convenience of ordering alcohol through rapid delivery services appeared to facilitate heavy, risky drinking by the younger Australians in our sample. Sixty-nine per cent of respondents who had alcohol delivered within two hours reported consuming five or more standard drinks on that

occasion, while 28 per cent consumed 11 or more drinks on that occasion.

The study also found that more than one-third of respondents aged 25 years and under (36 per cent) didn't have their ID checked when receiving their alcohol order, which increases the risk of underage drinking.

CAPR's conclusion was that both existing government regulation and industry self-regulation are inadequate. FARE agrees that inadequate age verification at point of delivery is a serious concern. Couple this with inadequate age verification at point of sale, as found by a recent audit of online licensees in NSW, and it is easy to see how children would be able to access alcohol.

**“The 2019 audit by Northern Sydney Local Health District of 504 licences and 215 websites in NSW found 60 per cent of online retailers did not require the purchaser to declare their date of birth or declare they are 18 years or over.”**

FARE has used the CAPR study to support a call for government to ban rapid delivery of alcohol (within two hours of purchase) and introduce mandatory ID verification at point of delivery.

FARE has also been working with the Public Health Association of Australia and the Public Health Advocacy Institute of WA to develop a *national policy position on online sales and delivery of alcohol* incorporating the findings from the research. This sets out the principles and rationale for taking regulatory action, and specific recommendations to reduce the risks posed by online sales and delivery of alcohol.

FARE says these recommendations should be urgently considered by the federal and all state and territory governments who have jurisdictional responsibility for keeping their communities safe from the harm of alcohol, which is known to kill almost 6,000 people and leads to 144,000 being hospitalised every year.

The research and advocacy group says online sales and delivery of alcohol must be regulated, and that compliance must be monitored and enforced by governments as a matter of public interest, otherwise this market disruption will undermine alcohol controls in Australia.

**Author: Dr Jenny Goodare**, Honorary Research Fellow La Trobe University and Senior Policy Officer FARE



Dr Jenny Goodare





# CANCER DNA IN THE CROSSHAIRS

By judiciously blocking cancer's ability to repair itself, Western Sydney scientists hope to develop more effective, gentler treatments for the disease.

**It may be counterintuitive, but stopping one of our bodies' repair mechanisms could be the key to successfully treating cancer, according to Western Sydney University's Associate Professor Liza Cubeddu and Dr Roland Gamsjaeger.**

Our DNA is constantly under attack — sunlight, even the process of cell replication can damage the genetic code. However, DNA repair molecules inside our cells quickly step in to repair the damage. Cubeddu and Gamsjaeger from Western's School of Science and Health are hoping to exploit these same molecules to help develop drugs to increase tumour vulnerability.

"Cancer cells divide more quickly than normal cells, so they need these DNA repair pathways much more urgently, which lets us target them specifically," explains Gamsjaeger.

"If we can block these DNA repair processes, we could make a cancer cell more sensitive to treatments such as DNA-damaging chemotherapies and radiotherapy," adds Cubeddu.

"This would mean doctors wouldn't need to administer these treatments for so long or at such high doses, which we're hoping will limit the side-effects."

In 2008, the team discovered a DNA repair protein molecule called hSSB1 and over the course of 10 years, homed in on the molecule's 'weak spots', which if targeted with a drug, could render it unable to repair DNA in cancer cells.

In 2018, Cubeddu and Gamsjaeger used nuclear magnetic resonance (NMR) spectroscopy to take a molecular snapshot of the 3D structure of hSSB1, allowing them to see the molecule's weak spots better

than ever before. The team have partnered with CARP Pharmaceuticals, which is developing cancer drugs to block hSSB1, based on the molecule's 3D snapshot.

"When we needed to find collaborators to solve a structural problem, Associate Professor Cubeddu and Dr Gamsjaeger were the obvious choice. Their research has helped drive our cancer drug development programme forward," says Professor Derek Richard from the Queensland University of Technology, who co-founded CARP Pharmaceuticals.

With DNA repair drugs already on the market, the scientists have high confidence their approach will lead to another therapy which, if used in combination with existing approaches, will help make treatments for cancer patients gentler and more effective.

## NEED TO KNOW

- DNA repair molecules fix cellular damage.
- Blocking these molecules could make cancer cells more sensitive to treatment.
- Researchers are developing drugs to block hSSB1, one of these repair molecules.

**Author: Dr Liza Cubeddu**, Associate Professor in Biochemistry, School of Science and Health.  
**Dr Roland Gamsjaeger**, Senior Lecturer in Biochemistry, School of Science and Health Western Sydney University

This research was supported by the Australian Government through the National Health and Medical Research Council, the William and Hilde Chenhall Research Trust, and Cancer Council Queensland.





# A REMARKABLE 30% DROP IN THE RATE OF CEREBRAL PALSY IN AUSTRALIA

In the most recent report launched by the Governor General of Australia, the Australian Cerebral Palsy Register (ACPR) demonstrated a remarkable 30% drop in the rate of cerebral palsy (CP), the most common physical disability of childhood which is lifelong.

**I**t is often accompanied by epilepsy, intellectual impairment, problems with speech and chronic pain. CP is due to an injury or problem with the developing brain, and can occur any time throughout pregnancy and during the first two years of life. There is no one cause of CP, rather many causal pathways, meaning many opportunities for preventive efforts.

This incredible decline from a rate of 1 in 500 to 1 in 700 livebirths occurred predominantly in extremely premature infants (born 20-27 weeks gestation), and at the other end of the spectrum, in term born infants (37+ weeks gestation), who are the most numerous. This has been attributed to the concerted efforts of researchers and clinicians in many fields including: midwifery, obstetrics, neonatology, paediatrics, basic science, epidemiology and public health.

Good research results from team work and the ACPR is a great example. This large collaborative effort includes deidentified data from each state and territory's CP Register. The NSW/ACT Register and the ACPR are hosted



at Cerebral Palsy Alliance, the oldest organisation of its kind in the world, founded by parents, which provides services to people with CP and other neurodevelopmental conditions. These CP registers only exist thanks to the financial support of the Cerebral Palsy Alliance Research Foundation (CPARF).

The CPARF was established by Cerebral Palsy Alliance in 2005 as a world first, dedicated to funding the best and brightest minds in CP research around the globe - all working together to drive achievements in prevention, treatment and cure of CP. The CPARF has developed a reputation as a world leader in fundraising and has to date invested \$49,000,000 in CP research. This important investment has been achieved through corporate and private philanthropy, fundraising events such as the Grace Gala and Steptember, government grants and the generosity of compassionate individuals.

Future prevention efforts that we are currently embarking on provide cause for optimism to further reduce the rate and severity of CP in Australia. An important example of current prevention strategies is *congenital cytomegalovirus* (cCMV) which is an infectious cause of sensorineural hearing loss and stillbirth. cCMV is also a known cause of CP. In research led by Cerebral Palsy Alliance Research Institute, The University of Sydney, investigators identified that close to 10% of children with CP had evidence of CMV DNA on their newborn screening cards, indicative of CMV viremia at birth. This finding suggested that CMV may make a larger contribution to the causal pathways to CP than previously recognised.

The good news is that there are *simple hygiene strategies that can reduce the risk of CMV infection in pregnancy* (see pictured).

**“ However, in Australia less than 20% of women are aware of cCMV and less than 10% of health professionals routinely discuss CMV prevention with pregnant women.**

The same researchers are now collaborating with families, obstetricians, midwives, neonatologists, virologists and perinatal infectious diseases specialists to promote awareness of these simple strategies with the aim of preventing some cases of cCMV.

In early 2020, Cerebral Palsy Alliance in collaboration with

CMV Australia and the Australian College of Midwives will be launching a new free cCMV e-learning course to support midwives to share information about CMV with women in their care.

Another possible avenue for prevention lies in pathways to CP that include congenital anomalies. Congenital anomalies are present in the baby at birth, and when these are found in the brain may be the cause of the child's CP, or if elsewhere in the body such as the heart can increase the risk of CP. Our new study (across registers in Australia and Europe) found that one in every four children with CP

have a major congenital anomaly and these children often have severe disability. Strategies already exist to decrease the risk of some anomalies (for example nutritional supplementation, management of maternal conditions, and avoidance of harmful substances), and our next phase of this research will be to identify how these strategies can be maximised and extended. The findings from this study have also led to a new collaboration with the World Health Organisation.

The genome revolution has also opened the door to other prevention efforts as genetics offers an opportunity to help us better understand the many biological mechanisms underpinning CP. However, making sense of this genetic data requires computational, clinical, experimental and genetic experts to work together. The International Cerebral Palsy Genomics Consortium (ICPGC) has been formed for this very purpose. It is an international community of clinicians, researchers and advocates working together to accelerate cerebral palsy genetic research. As part of a large collaboration, Cerebral Palsy Alliance is building a data base called the CP Commons, an online resource that will allow researchers and clinicians across the world to share and analyse de-identified DNA sequencing data from children and adults with CP, and their parents. This will be a big step forward for CP.

People who live with CP and their families have been central to the Cerebral Palsy Alliance throughout its long history. They have also been highly supportive of a focus on prevention of CP. In a world first study conducted by the Research Institute back in 2009 it was considered the number one research priority of people with CP and their families. Ten years later, Hannah Diviney (pictured with the GG) who is a spokesperson for the Australian Cerebral Palsy Register summed this up perfectly when she stated:

**“ This news is absolutely fantastic. If other kids don't have to go through what I have been through, well that is fine by me!”**

Collaboration has underpinned all of this work and together we will continue to work to improve health outcomes for families across Australia, and the world.

**Authors: Sarah McIntyre, Hayley Smithers-Sheedy, Shona Goldsmith, Yana Wilson, Lorraine McNuff and Nadia Badawi Cerebral Palsy Alliance**



**THE 5 STEPS TO REDUCE YOUR RISK OF INFECTION**



Wash your hands after activities like changing nappies



Don't share food, drinks, utensils, and avoid putting a child's dummy or toothbrush in your mouth



Avoid contact with saliva, kiss children on their forehead instead of the lips



Carefully dispose of nappies, used wipes and tissues



Clean toys that children have had contact with



# THE LAST WORD

The Last Word this issue goes to the Research Australia Board as they look back on the past year. Research Australia is uniquely positioned to convene, connect and influence greater health outcomes across the research pipeline. After all, as the collective voice for the sector, it is our mission is to use our unifying platforms to ensure health and medical research is a significantly higher national priority.



## CHRIS CHAPMAN

I am forever reminded of the importance of our unique position as the 'voice' and platform for the entire health and medical research pipeline. Based on some terrific outcomes this year and with on-going strong government and membership support, I am even more confident of the success of our influence into the future. Our strategic approach to improve health outcomes remains a strong motivator for all of us.

## PETER WILLS AC

I am proud to be part of the big outcomes generated from our small not-for-profit organisation since its inception to date. The impact of our events from the Victorian Philanthropy Conference to the Consumer Poll launch and our Signature Awards continues to fulfil our three key drivers, connect, engage and influence which is what keeps our membership strong and active. Our engagement and advocacy for health and medical research funding remain our core focus.



## A/PROF ANNETTE SCHMIEDE

I am so pleased to Chair the Research Australia's Health Economics Roundtables and be part of the robust conversations around this important area. This year's presentations have been extremely thought provoking and I look forward to continuing these discussions in the new year.

## PROFESSOR NICK FISK

Being both a Director of RA and Chairing their University Roundtable offers robust insight into how Research Australia puts its strategy into action. The topics discussed at the Roundtable regularly relate to RA's strategic themes of the value of data to research, embedding research in the health system, and smarter investment in research. Our quarterly Roundtables have become must go events for university leaders, where we hear from the countries movers and shakers in the health and medical landscape, debate policy and direction, and share best practice developments. Another example of how Research Australia acts on its tag line of connecting, engaging and influencing.



## NADIA LEVIN

The health and medical research sector continues to inspire me personally and professionally by the talent and innovation. We recognise the potential Australia has to be a world leader and pave the way through Frontiers research to make our country the healthiest in the world. I look forward to continuing our vision of unlocking this potential through the advocacy work we do.



## JENNY MORAWSKA

It's always rewarding to see the new members come on board as it shows how broadly the organisation is valued from small charities to large commercial entities. New and existing members alike we all seek to improve the quality of life in Australia.



## PROF ALEX MCMANUS

I have enjoyed my time on the Research Australia Board and University Roundtable over the past ten years. During this time the organisation has work tirelessly to progress health and medical research in Australia, and are now acknowledge as the prime body representing the entire research pipeline. I am proud to have had the chance to contribute to the alliance's endeavours with so many wonderful and hard-working Directors. I would particularly like to thank Mr Peter Wills AC for his leadership and guidance. What a shining example to us all. I wish Research Australia all the best for the future and I know they will continue to advocate successfully for the health and medical research sector



## PROFESSOR MARY FOLEY AM

I was delighted to present at some of Research Australia's key forums at Parliament House this year including the Pre-Election Statement Launch and the Consumer Poll Launch. Representatives across the Parliament certainly appreciate our whole of sector focus and I'm proud to be part of the work we're doing for health and medical research.



## A/PROF GREG KAPLAN

Improving health, curing and preventing disease is the key driver of medical research and the ultimate goal for researchers. The health industry relies too heavily on passive translation of knowledge through research presentations and publications. This pathway is inefficient – only 14% of completed research finds its way into a clinical practice or a primary care setting to directly benefit patients and the wider society. Success of translation depends strongly on the level of collaboration between researchers, clinicians, patients and industry. Research Australia provides a unique platform to foster this collaboration, to connect to all groups of stakeholders in the research translation pipeline, and to advance the progress of research directly into new programs and policies to support medical research and education.



## PROF MELISSA LITTLE

I am keen to ensure that health and medical research is appropriately recognised for its critical contribution to all of our lives, and I am looking forward to working with my fellow Research Australia Directors in 2020 to progressing these opportunities further.



## PROF DAWN FRESHWATER

It is a privilege to be able to contribute to an organisation such as Research Australia, I am very much looking forward to working with my peers in 2020 to embed research and development into the Australian health landscape.



## DR ANDREW NASH

RA's continued focus on the translation of Australian medical research in the new year will be one of our key endeavours. We've certainly delivered on our collaborative objectives since their inception in 2017 and I look forward further championing the commercialisation of Australian research for the benefit of both patients and the economy.



## PROFESSOR IAN JACOBS FAHMS

The role of Research Australia in advocating for the importance of health and medical research has never been greater. The success in developing ideas for the MRFF 'Futures' funding scheme is just one example of the great work of RA.





# RESEARCH AUSTRALIA

CONNECTING • ENGAGING • INFLUENCING

w [researchaustralia.org](http://researchaustralia.org)  
e [admin@researchaustralia.org](mailto:admin@researchaustralia.org)

## SYDNEY

384 Victoria Street,  
Darlinghurst NSW 2010  
p 61 (02) 9295 8546

## MELBOURNE

Level 5, 215 Spring Street,  
Melbourne VIC 3000  
p 61 (03) 9662 9420

