

# INSPIRE

RESEARCH AUSTRALIA SHOWCASES HEALTH & MEDICAL RESEARCH

## A CLINICAL TRIALS FOCUSED ISSUE

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**Clinikids –  
a marriage  
of research  
and practice**

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**Consumers  
leading the way  
in clinical trials**

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**Women boosting  
women in STEM  
on Wikipedia**

# FOREWORD

Welcome to the Spring edition of INSPIRE and its Clinical Trials focus. Clinical trials are the driver of access to better treatments and they have a massive impact on the Australian economy. Tremendous efforts have been made over recent years to streamline an often-frustrating system and find consensus around a national approach. This remains a work in progress. What we've sought to do in this edition, is to showcase the breadth of research being translated through clinical trials as evidence of what is being achieved, despite the challenges.



**R**ead on to hear from the Kids Cancer Project on their investment in the Clinical Trials Unit, ensuring that trailblazing science is being brought to Tasmanians. Congratulations to Professor Whitehouse and the team on really fulfilling their mission to become a centre of excellence for clinical and research training.

They say there is strength in numbers and Griffith University has submitted an article about the collaboration between clinicians, commercial industry and researchers which has

led to the world's first trial of modern, non-stick or bacteria resistant PICC materials.

I was also interested to read the Illawarra Health & Medical Institute's article about the potential links from childhood trauma to future health issues such as developing diabetes in pregnancy.

We're delighted at the announcement in May by Health Minister, the Hon Greg Hunt MP, that ten promising research projects have been successful in the first Frontiers funding round. This funding was awarded following an assessments process which utilised an expert international review panel. Our congratulations to Research Australia members in each of those projects. We are looking forward to great outcomes from this programme and have outlined the 10 projects in this issue. On a point of interest, the second round opens in October this year.

As the national peak body, Research Australia provides a neutral platform for the sector to come together on issues and opportunities across the sector. The last issue introduced our Event Overview segment so you

can see who's been talking to who about what at our various forums. We were pleased at the success of the 'Stronger Together' Conference in Victoria sharing innovative approaches to collaboration for successful Government funding.

The results from our annual consumer poll, Australia Speaks! 2019 are in and a report is being produced for our members and the sector. We look forward to your attendance at the launch in Canberra.

And last but by no means least and on behalf of the Board, I welcome Professor Melissa Little to our Board. Melissa heads the Kidney research laboratory at the Murdoch Children's Research Institute and is also a Professor in the Faculty of Medicine, Dentistry and Health Sciences, University of Melbourne. She is internationally recognised for her work and her pioneering studies and is a worthy winner of many awards and accolades including the GSK Award for Research Excellence.

I look forward to seeing you at the 2019 Awards.

**Nadia Levin**  
CEO & Managing Director





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**

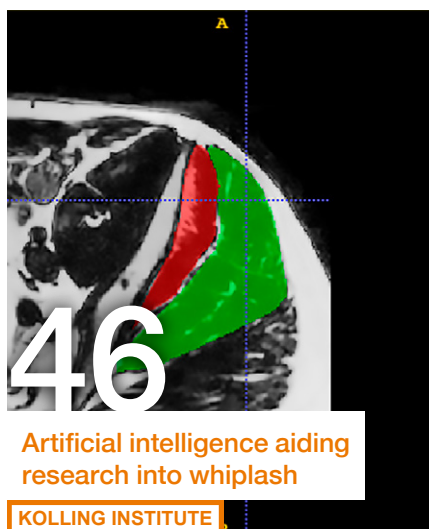
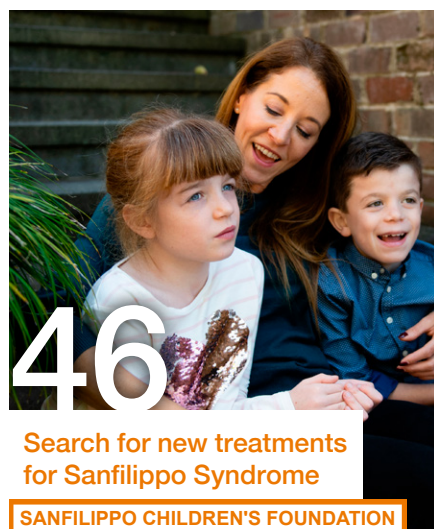
Find out more at [bupa.com.au/foundation](https://bupa.com.au/foundation)

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## Australian Health & Medical Research







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**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).

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## University Roundtable

The Research Australia University Roundtable on 17 May 2019 was held at Deakin University. Chaired by Research Australia Director and UNSW Sydney DVCR Professor Nick Fisk, it was attended by 22 representatives from 18 universities. Greg Mullins our Head of Policy gave his update on policy, the Federal election and the Budget.

### THE TOPICS AND SPEAKERS WERE AS FOLLOWS

Professor Julie Owens, DVCR, Deakin University drew on her previous experience as Pro Vice Chancellor Research at the University of Adelaide and her recent appointment as the DVCR of Deakin University to make some comparisons between the two institutions and in turn reflect on the role and future of Australian universities.

Professor Owens drew together some 'take home messages', including:

- Where education demand goes is crucial;
- Size matters, to both student load and revenue;
- It's all about the talent – getting, enabling, freeing up;
- Partnerships are essential;
- We must demonstrably reduce costs, increase effectiveness and deliver value for money to government, community and end users.

**Greg Mullins**, Head of Policy, Research Australia provided a roundup of policy related matters, including Budget announcements and election campaign commitments from the major parties that were of relevance to HMR. (The Federal election was held on the following day.)

**Professor Anna Peeters**, Director of the Institute for Health Transformation (IHT), and Professor of Epidemiology and Equity in Public Health at Deakin University spoke about **Food System Transformation for Health**

In 2018 Professor Peeters became lead Chief Investigator on an NHMRC Centre of Research Excellence in Food Retail Systems for Health (RE-FRESH). Anna's presentation focused on: the IHT and its work; how this led to RE-FRESH, and what RE-FRESH is seeking to achieve and the approaches it is taking.

**Alastair Furnival**, Evaluate and Greg Mullins sought feedback from attendees on the draft of the Evaluation Framework. Feedback from the Roundtable highlighted the strong emphasis in the Framework on economic returns, and its heavy reliance on health economists to support applicants and the evaluation panel when in short supply.

**Professor Christine Wells**, Deputy Program Leader of Stem Cells Australia (SCA), and a Director of the University of Melbourne's Centre for Stem Cell Systems, reviewed the progress of stem cell research as a still relatively new science and outlined the public funding for stem cell research in Australia via SCA and the organisations that preceded it.

Christine posed the question 'Why a Stem Cell Mission?' In answer, she highlighted the significant capacity in Australian research- and expressed the view that stem cell medicine in Australia is now a robust sector, ready for the next step toward clinical and commercial translation.



## HMR, ERA AND E&I

Professor Ross Coppel, FAHMS, Senior Deputy Dean and Director of Research, Faculty of Medicine, Nursing and Health Sciences gave a presentation on the NHMRC grant program, Excellence in Research Australia (ERA) and the recent Engagement and Impact (E&I) exercise.

Ross shared observations on the application processes for the NHMRC's new Investigator and Ideas grants, and about the most recent rounds of and the Engagement and Impact Assessment and noted the rise in performance across the board in ERA.



As Director of CSIRO's Health and Biosecurity Business Unit, Dr Rob Grenfell leads a broad portfolio covering: nutrition; eHealth; medical technology and diagnostics; and biosecurity, from weeds to Ebola. Rob gave the audience an overview of CSIRO and its activities, where the Division he leads fits within this structure, and how it relates to CSIRO's strategy and vision.

Rob then provided a 'tour' of the Division's different research and innovation areas and its facilities highlighting the interaction between the various internal research areas and collaborations beyond the CSIRO with universities, research organisations and health care providers. Rob also described CSIRO's Future Science Platforms.



Left: Chair, Prof Nicholas Fisk, Deputy Vice-Chancellor (Research) UNSW Sydney

Above: Greg Mullins, Head of Policy, Research Australia



## Victorian Government 'Stronger Together' Conference

Victoria undertakes world class health and medical research and with goals of better health outcomes, safer and more effective healthcare and commercialisation of research discoveries, it is an activity that resonates across the whole of Victoria's economy and community.

In May this year, the Victorian Government supported a Research Australia conference investigating philanthropic funding for health and medical research and how governments can leverage it through greater collaboration and co-funding.

The key objective of the conference was to share information on the power of collaboration from all stakeholders' viewpoints: state and federal governments, philanthropists, other funding bodies and not-for-profits who have succeeded in leveraging funding through collaborations.

Research Australia also launched a report on Non-Government Funding for Victorian Health and Medical Research and provided an update on our key findings about where sources of non-Government funding lie. It is hoped that outcomes from the interactive conference will help bring to light some of the challenges and opportunities in the sector which may affect policy and process around funding.



### A BIG THANK YOU TO THE FOLLOWING FOR KINDLY PRESENTING AT THIS EVENT:

The Hon. Jenny Mikakos  
Frank McGuire MP  
Assoc Prof Annette  
Schmiede  
Linda Cristine  
Georgia Hinton  
Erica Kneipp  
Kerryn Pennell

Harold Mitchell AC  
Prof Graeme Samuel AC  
Dr Shanny Dyer  
Prof Doug Hilton AO  
Prof Kathryn North AC  
Prof Ricky Johnstone  
Megan Donnell  
Chris Chapman



**Above:** Left Graeme Samuel AC, Chair Dementia Australia, Middle Chris Chapman, Chair Research Australia Right Harold Mitchell AC Australian Philanthropist and Humanitarian.

**Left:** Victorian Minister for Health The Hon. Jenny Mikakos and Research Australia Director and Executive Leader Bupa Health Foundation, Associate Professor Annette Schmiede.





[CLICK HERE TO REVIEW THE REPORT](#)



# NON-GOVERNMENT FUNDING FOR VICTORIAN HEALTH AND MEDICAL RESEARCH

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CONNECTING • ENGAGING • INFLUENCING



# RESEARCH AUSTRALIA HEALTH & MEDICAL RESEARCH AWARDS 2019

The Peter Wills Medal, Great Australian Philanthropy Award and GSK Award for Research Excellence only have an outright winner which is embargoed until the Award Ceremony on November 14. However finalists in the other categories are:

## GRIFFITH UNIVERSITY DISCOVERY AWARD

- **Dr Berhan Ayele Haile**, the Burnet Institute – nominated by Professor David Anderson, the Burnet Institute
- **Dr Alexandra Bannach Brown**, Bond University – Nominated by Associate Professor Kevin Ashton, Bond University
- **Dr Christine Keenan**, Walter & Eliza Hall Institute – Nominated by Associate Professor Daniel Gray, Walter & Eliza Hall Institute
- **Dr Lucia Romani**, UNSW Sydney – Nominated by Scientia Professor John Kaldor, UNSW Sydney

(in alphabetical order)

## HEALTH SERVICES RESEARCH AWARD

- **Prof Claire Jackson**, University of Queensland – Nominated by Dr Lauren Ball, Griffith University
- **Prof Glenn Marshall AM**, Children's Cancer Institute – Nominated by Conjoint Professor Michelle Haber AM, UNSW Sydney
- **Prof Libby Roughead**, University of South Australia – Nominated by Associate Professor Rachael Morton, Health Services Research Association of Australia & New Zealand
- **Prof Karin Thursky**, Peter MacCallum Cancer Centre & Royal Melbourne Hospital – Nominated by Professor Mike McGuckin, University of Melbourne

(in alphabetical order)

## DATA INNOVATION AWARD

- **Associate Prof Adam Dunn**, Macquarie University – Nominated by Professor Enrico Coiera, Macquarie University
- **Prof John Lynch**, University of Adelaide – Nominated by Professor Andrew Zannettino, University of Adelaide
- **Matthew Phillips & the Lifespan Data Team**, Black Dog Institute – Nominated by Assistant Prof Alison Cleave, ANU
- **Prof David Wilson**, Burnet Institute – Nominated by Professor Brendan Crabb AC, Burnet Institute

(in alphabetical order)

## ADVOCACY AWARD

- **Prof Gordon Lynch**, University of Melbourne – Nominated by Prof Matthew Watt, University of Melbourne
- **Mr Duncan McPherson OAM** – Nominated by Associate Professor Philp Beale, Australia New Zealand Gynaecological Oncology Group
- **Annabelle Wilson**, Cure Brain Cancer Foundation – Nominated by Mr Daniel Chapman, Cure Brain Cancer Foundation.

(in alphabetical order)

## FRONTIERS RESEARCH AWARD

- **Dr Lisa Gillinder**, Mater Research Institute – Nominated by Professor Maher Gandhi, Mater Medical Research Institute
- **Prof Sailesh Kumar**, Mater Research Institute – Nominated by Professor Maher Gandhi, Mater Medical Research Institute
- **Associate Prof Jeremy Micah Crook & team**, University of Wollongong – Nominated by Professor Buzz Palmer, Monash University

(in alphabetical order)





# RESEARCH AUSTRALIA HEALTH & MEDICAL RESEARCH AWARDS 2019

## *Invitation*

**DATE** Thursday 14 November

**TIME** 6.00pm UNSW Sydney Welcome Reception  
7.00pm Award Ceremony

**VENUE** Metropolis Ballroom  
3 Southgate Ave, Southbank Melbourne

**DRESS** Black Tie

**TICKETS** \$280 each or  
\$2520 for a table of 10

**RSVP** 28 October

**Book your tickets online at**  
**[researchaustralia.org](http://researchaustralia.org)**

For more information call (02) 9295 8546

### 2019 AWARDS SPONSORS









# Frontiers funding

Recipients of the first Stage One funding round of the Medical Research Future Fund (MRFF) Frontiers initiative which Research Australia advocated for so strongly, will receive funding of up to \$1 million each over one year to develop detailed plans for their cutting-edge research projects. The projects will be able to apply for Frontiers Stage Two with the opportunity to secure up to five years funding of \$10 million to \$20 million per annum to realise their ground-breaking research.



**F**rontiers provides enormous possibilities for Australia's talented researchers. These projects have the potential to save and protect millions of lives.

1

\$999,956 for a world first research project to harness next generation brain imaging technology for diagnosis and treatment of epilepsy. Professor Jackson and The Florey Institute will collaborate with Australian and international leaders in epilepsy, neuropsychological testing and genetic testing in working groups to dramatically improve epilepsy care and patient experiences.

2

\$924,100 for research to develop a new interface between the brain and a machine, to help people regain eyesight, movement or other nerve functions. The Cortical Frontiers: Commercialising Brain Machine Interfaces project is headed by Professor Arthur Lowery, Professor of Electrical and Computer Systems Engineering at Monash University. The device was originally developed to restore vision, but can be repurposed to provide stimulation of many neural functions. The Cortical Frontiers project will work with doctors and patients to identify the two most promising applications of the technology for development.

3

\$998,731 allocated for research towards a national database of antibiotic resistance, to allow resistant strains to be traced, isolated and treated. This project is headed by Professor Steen Djordjevic of the Proteomics Core Facility at the University of Technology Sydney. Antimicrobial resistance (AMR) represents the greatest health challenge facing humanity. Without a solution, it is forecast to cause 50 million deaths a year worldwide by 2050. The Trace, Track and Tackle project will use sensor technologies, data, knowledge, and artificial intelligence to develop a nationwide system, called OUTBREAK, help in the fight against antibiotic resistant bacteria.

4

\$964,700 for research into large scale use of an Australian method for controlling the spread of Zika virus, dengue fever and other mosquito-borne diseases. The Innovative Public Health Program Against Mosquito-Borne Diseases is headed by Professor Scott O'Neill, of the Institute of Vector-Borne Disease at Monash University. Professor O'Neill and his team pioneered the use of a naturally occurring bacterium called Wolbachia to reduce the ability of mosquitoes to transmit certain viruses. The method has been successfully tested in small field trials and a larger field site in Townsville in Queensland

5

\$895,346 for multidisciplinary research to develop new technologies to improve women's sexual and reproductive health. The EVE-M — Enhancing the Vaginal Environment and Microbiome—Initiative is headed by Professor Gilda Tachedjian of the Burnet Institute. The EVE-M initiative will develop and commercialise a series of pioneering technologies to improve women's sexual and reproductive health. The ultimate goal is to reduce the health burden and cost of bacterial vaginosis and sexually transmitted infections in Australia and around the world. As well as the Burnet Institute, the EVE-M Initiative includes Swinburne University of Technology, Melbourne Sexual Health Centre, Deakin University's Waurn Ponds Campus, and Family Planning NSW.

6

\$960,000 for intensive research into new 4D diagnostic technology to allow accurate assessment of lung function in people of all ages, including the very young and old. The Australian Lung Health Initiative aims to deliver an original technology that is rapid, easy to use and safe, with less than 10 per cent of the radiation used by x-rays. Patients would not have to remain still or follow instructions, making it suitable for infants, children, older people and the very sick who are difficult to assess with current technology. Professor Andreas Fouras is founder, chairman, and chief executive of 4Dx. The Australian Lung Health Initiative was formed to bring together world-leading Australian scientists, engineers, manufacturers and medical researchers to revolutionise lung screening and treatment.



7

\$1 million for a world first Australian research project using the latest genome editing technology to rapidly detect and identify infectious disease and antimicrobial resistance. The c-FIND: CRISPR Frontier Infection Diagnostics to Detect Infection project is led by Professor Marc Pellegrini of the Walter and Eliza Hall Institute of Medical Research in Melbourne. There is an urgent, unmet need around the world for rapid and accurate identification of infectious disease in patients, to combat antimicrobial resistance and mitigate the devastating consequences of epidemics and pandemics. This teams work has the potential to dramatically change the way infectious diseases are diagnosed, providing clinically relevant answers in real time, and speeding time to treatment.

8

\$1 million for a world first Australian research project using therapeutic ultrasound to treat brain disorders, including dementia. The Therapeutic Ultrasound for the Treatment of Brain Disorders project is headed by Professor Juergen Goetz, Director of the Centre for Ageing Dementia Research at the University of Queensland's (UQ) Queensland Brain Institute. Last year, around 450,000 Australians were living with dementia. Without a medical breakthrough, this number is expected to rise to more than a million by 2028. The multidisciplinary therapeutic ultrasound program will build on the UQ's successful use of ultrasound to improve the effectiveness of drugs used to treat Alzheimer's disease. It will aim to deliver an innovative technological platform combining ultrasound and essential auxiliary technology to effectively treat Alzheimer's and other brain disorders.

9

\$747,596 for a world first Australian research project to test a new biomedical technology to deliver spinal cord stimulation as a treatment for cerebral palsy. The Cerebral Palsy Treatment by Closed Loop Electrical Stimulation project is headed by Professor John Parker, founder and chief executive officer of Saluda Medical Pty Ltd and Adjunct Professor of Biomedical Engineering at the University of New South Wales. Cerebral palsy is an incurable disease characterised by spasticity. There is no current cure although various treatments can provide some relief from symptoms. Currently more than 34,000 Australians are affected by cerebral palsy. Every 15 hours, a child is born with cerebral palsy in Australia, making it the most common form of childhood physical disability.

10

\$1 million for the development of new technologies to care for stroke victims before they reach hospital as one of the first funded projects. More than 56,000 Australians have strokes every year and around half a million people are living with the effects of stroke. The multidisciplinary research alliance on pre-hospital care for stroke is headed by Professor Geoffrey Donnan of the University of Melbourne and includes stroke experts, engineers, computer scientists, paramedics, healthcare providers and non-government organisations.



# CONSUMERS LEADING THE WAY IN CLINICAL TRIALS

Consumers are vital to helping shape and advance clinical trials by lending their personal experience, working with professionals to improve the design and conduct of clinical trials.





**To maximise the advantages of consumer engagement, Australian Clinical Trials Alliance (ACTA), the peak body for clinical trials networks, clinical quality registries and clinical trial coordinating centres, formed a reference group to explore how to strengthen consumer involvement and engagement in developing, conducting and reporting clinical trials.**

ACTA's Strengthening Consumer Engagement reference group recently surveyed consumers, researchers and medical research organisations to gauge attitudes toward, and discover the benefits of, collaborating with consumers.

The subsequent report produced 'Consumer Involvement in Clinical Trials: Consultation Report' is available in the Resources area of the ACTA website, [clinicaltrialsalliance.org.au](http://clinicaltrialsalliance.org.au). It shows that attitudes toward consumer involvement in trials were overwhelmingly positive, both from consumers themselves and from clinician-researchers. Consumers who were invited to participate felt positive about clinical trials and became advocates for the research process. Researchers also felt that consumer involvement allowed them to refine their trials most effectively—from recruitment, through to the overall design.

***“The investigator-led trial sector already engages with and values consumer involvement, but the survey highlighted the need for more support to sustain these partnerships. Opportunities to strengthen and foster these collaborative relationships needed adequate support to actively involve and champion consumers in every stage of clinical research.”***

ACTA took the opportunity to celebrate the importance of consumers on International Clinical Trials Day 2019. This year, the annual National Tribute & Awards Ceremony, honouring the remarkable Australians who advance our health system, included the inaugural Consumer Involvement Award.

The 2019 winner was the TORPIDO30/60 Trial for its inclusion of consumer Melinda Cruz. Cruz, founder of Miracle Babies, acknowledged consumer expert and mother of three babies who were born preterm, was invited to be a member of the Trial Management Committee for the study and was part of the team that worked with the Hunter New England Human Research Ethics Committee to eventually gain a waiver of consent for the trial. This meant that all preterm babies could benefit by entering the study, including those born at night, on weekends, or in emergencies—a group often missed in trials. After 30 years without clarity or evidence, TORPIDO 30/60 was able to discern which level of oxygen was most beneficial for preterm babies.

To encourage these important relationships, ACTA has consulted with the sector to discover how to facilitate positive working relationships with consumers. The result is the Consumer Involvement and Engagement Toolkit, created by ACTA in partnership with CT:IQ. The Toolkit gathers existing or adapted national and international guidance and tools to facilitate active and collaborative consumer involvement and engagement along the lifecycle of a clinical trial. The toolkit in its final form will be available online later in 2019.

Australian Clinical Trials Alliance has also encouraged consumer delegates to the ACTA International Clinical Trials Conference, to be held at the International Convention Centre in Sydney, 2-5 October 2019, by awarding five free registrations to consumers who are involved with clinical trials, along with including consumer-related topics throughout the conference program.

By connecting consumers with clinical trials at all stages of the process we will see the development of a stronger and more efficient health care system.

All Australian Clinical Trials Alliance resources and information can be found on the ACTA website <http://www.clinicaltrialsalliance.org.au/>

**Author: Australian Clinical Trials Alliance (ACTA)**



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**ACTA International Clinical Trials Conference**

**2-5 OCTOBER 2019**

**ICC SYDNEY | AUSTRALIA**

**REGISTER NOW**



**[clinicaltrialsconference.com.au](http://clinicaltrialsconference.com.au)**





**WE HEAR YOU**

# INVESTIGATING ATTITUDES TOWARD HEARING DEVICES

At age 67, Mary received a cochlear implant on her left side. There were tears of joy when she recognised sound coming from that side for the first time in years. Within 6 months, she was participating in conversations more confidently and regaining a social life.









**D**escribed as a miracle by many, the sensation of sound that cochlear implants deliver to the profoundly deaf or those that derive little benefit from hearing aids, is an example of the collaboration between research, medicine and technology at its best.

Why then, have fewer than an estimated 5% of adults in Australia who would benefit from cochlear implants taken up the opportunity?

### **COLLABORATION**

Researchers from the Australian Institute of Health Innovation (AIHI) have collaborated with Cochlear Limited to find answers to this question. Together they undertook a unique qualitative research project to investigate attitudes towards hearing treatments. What they uncovered was professional and consumer uncertainty and a health system that is hard to navigate.

Leading the AIHI team is Professor Frances Rapport, an internationally top cited qualitative health researcher and Professor of Health Implementation Science at AIHI.

Professor Rapport's expertise in implementation science focusses on ensuring research has real world impact.

"Collaborating with industry and consumers accelerates the impact that our research can have where it is most needed. With Cochlear Limited, we can deliver highly relevant results to hearing impaired consumers, their families and the health system," explains Professor Rapport.

Hearing loss is a growing healthcare pandemic and has been identified by the World Health Organisation as one of its top priorities, with more than 46 million people in high income countries like Australia living with disabling hearing loss.

Despite cochlear implants having been available for decades and proven to be a safe and effective technology, uptake in Australia and worldwide is low.

### **BARRIERS AND FACILITATORS**

In order to uncover the barriers and facilitators to uptake, AIHI and Cochlear Limited recognised the value of involving consumers, their families and healthcare professionals in the process of research design.

Cochlear Limited's Clinical Studies Program Manager Chris Warren points out that pre-trial qualitative research is rarely conducted in audiology.

***"This study is one of the first of its kind to rigorously analyse clinician and patient feedback to inform design of a randomised clinical trial," he said.***

AIHI researchers, with their depth of expertise in qualitative research and implementation science, utilised a range of research methods including interviews, qualitative open-ended surveys and questionnaires to discover the attitudes to hearing devices of healthcare professionals and consumers. They also explored how much these groups knew about hearing loss in general, where to get help, and what avenues they preferred as sources of information on hearing devices.

In preparation for the research, it was recognised that some communication methods may be preferred by people with hearing impairment and so options such as email, face to face meetings and phone interviews were offered to participants.

"It is important to ensure our research is relevant to the lived experience of people with profound hearing loss as





well as to those healthcare professionals assisting them,” said Professor Rapport.

Professor Rapport’s research has shown that consumers and healthcare professionals are uncertain about when it is appropriate or beneficial to investigate the use of a hearing device. Also, that people are not confident of the steps to take to begin the journey—reflecting the Organisation for Economic Cooperation and Development (OECD) statement that the Australian healthcare system is too hard for people to navigate.

### **BARRIERS AND FACILITATORS UNCOVERED INCLUDED:**

- Consumers often do not know where to seek help when they notice a hearing impairment in themselves or a family member.
- GPs would benefit from more training to identify hearing impairment and knowing when to refer to an ENT specialist or audiologist.
- Audiologists can be limited in their product offerings due to commercial ties with specific hearing device suppliers.

Recognising a sector-wide challenge, Cochlear Limited and AIHI aim to make the pathways to care more transparent and accessible.

### **RESEARCH DESIGN**

Cochlear Limited is planning a randomised controlled trial (RCT) that will inform the development of evidenced-based guidelines for determining which hearing device (hearing aid and cochlear implant) is most suitable given each patient’s degree of hearing loss and daily listening needs.

Importantly, the research AIHI has undertaken with consumers and healthcare professionals will ensure

the RCT has real-world applicability. Results from the qualitative research will be used to not only inform the design of the RCT but also the dissemination of information during and after the research phase.

Professor Rapport explains “We now understand that there is uncertainty among GPs about how and when to refer people with hearing loss. This knowledge can inform the design of the RCT which will in turn seek to provide readily accessible, high quality evidence-based guidelines for referrals.”

**“We also appreciate that the burden of hearing loss can be great for the patient and their family and can lead to mental health issues and impacts on employment and relationships. The cost of hearing devices is also an ongoing burden, with expenses including batteries and upgrades. There is also a fear of surgery.”**

The collaboration between AIHI and Cochlear Limited provides a valuable opportunity to incorporate this knowledge into the design of the RCT ensuring that the outcomes reflect the real need of the hearing-impaired community, their families and healthcare professionals.

**Author: Professor Frances Rapport**, Professor of Health Implementation Science, Australian Institute of Health Innovation, Macquarie University and Academic Lead, MD Research, Macquarie University.



# REDESIGNING CATHETER MATERIALS TO TRANSFORM HEALTHCARE







Associate Professor Amanda Ullman  
working in the Nathan campus lab.





**Alliance for Vascular Access Teaching and Research group shot at the Nathan campus lab. (left to right: Professor Claire Rickard (co-Lead), Dr Nicole Marsh, Associate Professor Amanda Ullman, Dr Gillian Ray-Barruel, Ms Jessica Schults, Ms Emily Larsen, Associate Professor Andrew Bulmer, Dr Jarod Horobin, Professor Marie Cooke (co-Lead), Associate Professor Joshua Byrnes, Ms Tricia Kleidon).**

## **INNOVATIONS IN CATHETER MATERIALS SET TO SIGNIFICANTLY REDUCE PATIENT HARM.**

Throughout the world, medical treatment for millions of people requires the insertion of peripherally inserted central catheters (PICCs) to provide treatment and critical medication for acute and chronically ill patients. PICCs are long tubes, mainly inserted in the upper arm into a large vessel, and then threaded to the opening of the heart.

In the last 40 years, we have seen a rapid acceleration in PICC use, which allows treatment for anti-cancer therapies, nutrition and antimicrobials to be administered through high blood volume pathways.

Despite being considered safer, easier to insert and more cost-effective than more invasive catheter devices, these devices are rife with complications.

At least 30% of PICCs fail before treatment is complete, due to infection, blockage, dislodgement or vessel damage.

In Australia, over 42,000 PICCs fail per year with patients and families bearing the costs of repeat admissions, emergency department visits, additional procedures, prolonged therapy, and chronic vessel depletion.

As well as the physical pain and distress caused to patients, failed PICCs cost the Australian hospital system approximately \$216 million annually.

But what if PICC materials were slippery or antiseptic-coated, so blood clots and bacteria couldn't stick?

Researchers like Associate Professor Amanda Ullman from the Alliance for Vascular Access Teaching and Research (AVATAR) at the Menzies Health Institute Queensland are working towards exactly that.

As the world's largest research collaborative in their field, the AVATAR team have been on a mission to put an end to vascular access complications since 2007.

Their world-renowned team is currently undertaking a clinical trial to put an end to preventable PICC complications and failures.

"Patients requiring peripherally inserted central catheters, or PICCs, are being treated for significant healthcare conditions, such as cancer and severe infection. They deserve the absolute best of our science, innovation and healthcare system," says Associate Professor Ullman.





### ABOUT AVATAR

Since 2007, the Alliance for Vascular Access Teaching and Research (AVATAR) has been on a mission to put an end to vascular access complications. AVATAR undertakes committed scientific work to improve health services and patient outcomes, to rigorously and independently test products and practices, and to promote local and global networks for multidisciplinary practice development. Their work has led to changes in hospital protocols worldwide, providing patients with a better healthcare experience and saving global healthcare providers hundreds of millions of dollars.

**“ We have the opportunity to prevent patient harm associated with infections and thrombosis by harnessing technology in our healthcare systems.**

I am currently working to optimise health service delivery for patients, so they are able to receive the treatment they need, without complications.”

In a world first clinical trial, our Interdisciplinary team is directly comparing two emerging technologies against current practice.

These technologies involve the PICCs being either coated with Chlorhexidine Gluconate (a common antiseptic) or being made of hydrophobic catheter materials (i.e. they repel water).

They also incorporate advanced valve technologies that resist backflow and reduce blood reflux.

In previous laboratory studies, these new materials prevented bacterial growth, and thrombus accumulation - which, in the clinical setting, should drastically reduce significant complications such as bloodstream infection and blood clots.

By reinventing the design and materials of PICCs, we can potentially improve the health outcomes of millions of patients worldwide,” she said.

#### Author: Associate Professor Amanda

**Ullman** is a paediatric nurse, and world-class researcher at the Menzies Health Institute Queensland and the Griffith University School of Nursing and Midwifery. Currently supported by a National Health and Medical Research (NHMRC) Fellowship, her research focuses on the prevention of complications associated with paediatric hospital admissions, especially those related to central venous access devices.



# HOW EXPOSURE TO TRAUMATIC EXPERIENCES IN CHILDHOOD MAY PUT WOMEN'S HEALTH IN PREGNANCY AT RISK.

**Adverse Childhood Experiences such as abuse and family conflict may be putting the health of women and future generations at risk.**

**O**ver 50,000 children were abused or neglected in Australia in 2017-18, often by someone they know and should be able to trust. Although many cases are not reported, the number of children exposed to trauma is increasing.

A new epidemiological study has shown exposure to childhood trauma is linked with the risk of developing diabetes in pregnancy (gestational diabetes).

The research was led by Dr Danielle Schoenaker, Research Fellow at the Illawarra Health and Medical Research Institute (IHMRI) and the School of Medicine at the University of Wollongong.

"Our study showed that women who grow up in stressful environments are more likely to develop gestational diabetes if they had developed depressive symptoms in adulthood prior to becoming pregnant," says Dr Schoenaker.

## **COMPLEX LINK BETWEEN CHILDHOOD ADVERSITY AND DIABETES IN PREGNANCY**

Gestational diabetes affects 1 in 10 women during pregnancy, and has short-term and lifelong health consequences for both mothers and their children.

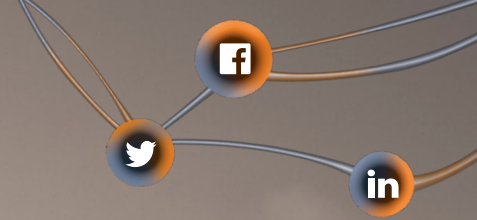
During pregnancy, gestational diabetes increases the risk of hypertensive disorders, excess foetal growth, operative delivery and admissions to neonatal special care. It also increases the risk of obesity, diabetes and cardiovascular disease later in life, in both the mother and offspring.

Importantly, this creates a vicious circle of poor cardiometabolic health across generations, which calls for new strategies to interrupt this cycle.

Dr Schoenaker analysed data from over 6,000 Australian women aged between 18 and 42 years who reported on a number of adverse events they may have experienced during childhood, their lifestyle and health before pregnancy, and whether they were diagnosed with gestational diabetes.

**“The findings of our study indicate that women exposed to three or more traumatic experiences in childhood were two times more likely to experience depressive symptoms before pregnancy,” says Dr Schoenaker.**





“Women were at higher risk of developing gestational diabetes if they had experienced childhood trauma and subsequently developed depressive symptoms in adulthood.”

Dr Schoenaker adds, “Although these women were also more likely to have an unhealthy diet, to be overweight or obese and to smoke, their poorer lifestyles did not explain the higher risk of gestational diabetes”.

“These findings therefore suggest that chronic exposure to stress across childhood and adulthood may be linked with gestational diabetes risk via physiological pathways.”

Traumatic events experienced early in life can be damaging to the development of the brain when it is most vulnerable. Neural development relies on the interplay of genes and the environment, and early adversity that leads to chronic high levels of stress can promote neuroendocrine disruptions that have been linked to glucose metabolism.

### HOW A LIFE COURSE APPROACH CAN HELP IMPROVE HEALTH OF CHILDREN AND FAMILIES

The study findings highlight the importance of prevention efforts that ensure optimal mental health across the life course – including during childhood and prior to pregnancy (preconception).

To reduce the number of children exposed to traumatic events, intensive family support services are available in Australia.

According to Australian Institute of Health and Welfare data on child protection, 335 intensive family support providers delivered services to about 33,100 children in 2017-18.

These family services help identify and treat behavioural and social risks of parents, such as managing stressful situations and using positive parenting strategies.

During the preconception period – which from an individual's perspective starts when a couple decides they want to have a baby – may also provide an opportunity for health care providers to identify and support women exposed to childhood adversity and treat depressive symptoms they may have.

Evidence on the effectiveness of preconception interventions for improving outcomes for mothers and their children is scarce, and Dr Schoenaker's current research aims to inform the development of such interventions.

Before, during and after pregnancy, it is critical for clinicians to understand the relationship between adverse childhood experiences and medical diagnoses such as gestational diabetes.

“We need to understand that there is something going on, beyond lifestyle factors, and be curious about a deeper understanding of the mechanisms that underpin these associations,” says Professor Leonie Callaway, co-author of the research, and Obstetric Physician at the Royal Brisbane and Women's Hospital.

“To provide compassionate clinical care, it is important to understand the depth of difficulty many of our patients have struggled with.”

The study on The Role of Childhood Adversity in the Development of Gestational Diabetes was recently published in the American Journal of Preventive Medicine.

This study was based on data from the Australian Longitudinal Study on Women's Health (also known as Women's Health Australia), which is funded by the Department of Health.



**Author: Dr Danielle Schoenaker** is an epidemiologist, and Research Fellow at the Illawarra Health and Medical Research Institute (IHMRI) and the School of Medicine at the University of Wollongong.



# THE KIDS CANCER

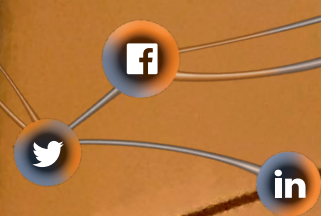
## CLINICIAN PROFILE – PROF JOHN HEATH

In order for Macy Menzie to participate in vital clinical trials over 12 months, the seven-year-old had to fly from Hobart to Melbourne every three weeks.





# ER PROJECT



**H**er condition, neurofibromatosis type 1, had resulted in a brain tumour in her optic pathway and traditional treatments were not working.

Up until two years ago, seriously ill Tasmanian children like Macy were forced to travel to the mainland to take part in clinical trials. Then Associate Professor John Heath decided enough was enough.

“Macy essentially had the equivalent of a stroke,” explains Associate Professor John Heath, from Tasmania Health Service and the Royal Hobart Hospital.

“She has a left-side weakness in her body and she’s got visual impairment. What we’re trying to do is to prevent her from going blind, and potentially it’s life threatening beyond that.”

In 2017, after Professor Heath played a key role in establishing a Children’s and Adolescent/Young Adult Cancer Clinical Trials Unit at Royal Hobart Hospital, Macy was finally able to dump her intense travel schedule to be treated locally.

The Clinical Trials Unit, now funded by a pledge of more than \$300,000 over five years from The Kids’ Cancer Project, is ensuring that trailblazing science is being brought to Tasmanians. It means children and their families can avoid the need to travel for potentially life-saving treatment at a time that they can least afford to do so.

“I had worked at the Royal Children’s Hospital in Melbourne for many years and was aware of the number of patients travelling from Tasmania, where clinical trials were not available,” said Professor Heath.

“It’s been well established for many years that the health outcomes for children with cancer are very closely related to the availability of, and participation in, clinical trials. Those two factors made it clear that we needed to bring Tasmania into that clinical trial space,” he said.

Also beyond dispute, Professor Heath stated, is the fact that the best outcomes for seriously ill children occur when they are able to be treated locally and experience as little disruption to their lives as possible.

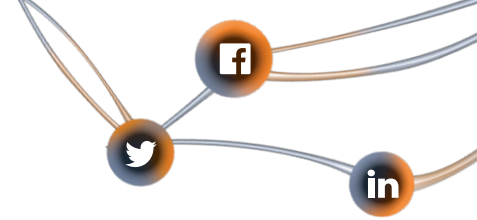
“You’re not just dealing with the treatment, you’re dealing with siblings and parents and friends,” Professor Heath said.

The ability to not have to travel is a big factor, because it means they can still attend school, they can sleep in their own bed, they can enjoy their usual support networks. Then, from a financial point of view, it means the parents can often continue to work in some capacity and not have to spend a great deal of money on travel and accommodation and eating out, etc,” he said.









In the two years since the Clinical Trials Unit has been established in Hobart, over 100 children have participated in clinical studies and five have had treatment included as part of that study.

But it's not just about the children. The Unit also benefits the local medical community in terms of knowledge, exposure to leading research from around the globe and participation in broader national and international trials.

"The other part of it, which is not part of the clinical trials but is a corollary of it and has been, to a large extent, funded by The Kids' Cancer Project, is that it has allowed us to participate on the national stage," Professor Heath said.

"We are now a full member of ANZCHOG (the Australian and New Zealand Children's Haematology/Oncology Group) and that allows us to participate in the exchange of knowledge, keeping up to date with things going on nationally and internationally, and contributing to policy. That's an indirect benefit, but it's an absolutely vital one."

The Kids' Cancer Project, Professor Heath said, has allowed Tasmania Health Service to match international best practice and, at the same time, benefited the children and families of Tasmania.

The success of the Clinical Trials Unit and its involvement in vital research has also meant it has been able to apply for further funding from the National Health and Medical Research Council.

That's important, because the Unit's future success is all about funding, Professor Heath said.

***“If we don't have the money then we can't employ people, so it could all end overnight,” he said. “That would be a disaster. If we're able to continue then we'll open more clinical trials, such as one that is currently coming down the line from Europe for the treatment of leukaemia.”***

The entire program has a very real effect on patients, Professor Heath said. Young Macy, for example, has been able to access through a compassionate-use program a number of revolutionary drugs that have not previously been listed.

"This is possible because we've been able to show the drug company that we will monitor her as though she's on a clinical trial," he said. "We can do this because we now have the infrastructure, and particularly an experienced clinical trials coordinator, to collect the data and interact with the company with regards to side effects, etc."

"So now a ten-year-old girl is benefiting from being on a drug that would be seen as cutting-edge in Paris, London or New York, but she's able to do it at home in Hobart."

**Author: The Kids Cancer Project**



# COLLABORATION IN CLINICAL TRIALS

Barwon Health and Deakin University (BH-DU) have partnered to develop innovative solutions to the major health challenges of our times. It is a dynamic collaboration that brings together the largest regional health services in Australia, and a University with expertise in clinical trials, public health, epidemiology, information technology, basic science, health economics and implementation science.



## A New Treatment Trial for Bipolar Disorder



People wishing to take part in the trial can obtain more information from:

Geelong: 0402 196 595  
 Melbourne (Richmond): 03 9487 4658  
 Melbourne: 0413 898 610  
 Brisbane: 0481 189 040

[www.mangosteenbipolar.com](http://www.mangosteenbipolar.com)  
[mangosteenbipolar@barwonhealth.org.au](mailto:mangosteenbipolar@barwonhealth.org.au)

**Do you have bipolar disorder?**  
**Are you looking for something more than your usual treatment?**

### The Aim

The project aims to determine if an extract of mangosteen fruit helps to reduce symptoms of depression in those with bipolar disorder.

### The Reason

It is believed that the symptoms of bipolar depression may be partially caused by increased levels of inflammation and oxidative stress (an imbalance in the levels of antioxidants) in the brain. There is evidence to suggest that the rind of the fruit from the Mangosteen tree contains bioactive compounds that may be beneficial in reducing oxidative stress, which may in turn reduce the symptoms experienced by those with bipolar depression.

### Key Points for Participants

- The trial will NOT involve any costs.
- People will continue their usual treatment.
- The study has two arms, the placebo arm which will not contain mangosteen fruit extract and the active arm which does contain mangosteen fruit extract.
- The treatment trial will last 24 weeks with regular 4 weekly assessments.
- We will require your commitment to taking two capsules once a day with food.
- You will attend a follow up visit 1 month after the completion of the study.
- Once enrolled in the study you will receive re-imbursement of travel expenses up to \$20 at each visit completed.

### Persons Eligible for the Trial

Anyone 18 years or older with a diagnosis of bipolar disorder and currently experiencing low mood.



## NEW DRUG FOR ICE

We are trialling a new medication to help people manage their ice use.

N-acetylcysteine, or NAC, has been shown to reduce cravings for ice. We are conducting a clinical trial to see whether it can help people reduce their ice use. The trial involves taking NAC daily for 12 weeks. Participants will either receive NAC or a placebo.

Further information on the trial is available at [www.nicetrial.info](http://www.nicetrial.info) or

visit us on [Facebook \(N-ICE trial\)](https://www.facebook.com/nicetrial).

If you are interested in participating please contact

**Margie** on mobile **0415 313 701** or email [n-ice@deakin.edu.au](mailto:n-ice@deakin.edu.au)

This a multi-site trial funded by the National Health and Medical Research Council (APP1128147). It is being conducted by Deakin University and Barwon Health.

The trial has been approved by Barwon Health Human Research Ethics Committee.

**ICE CRACK METH SKATES TINA CRYSTAL ICING FIRE GLASS SHARD**

**T**he focus of research undertaken by the BH-DU partnership includes early childhood and infant development; mental health; the interface between mental and physical health; emerging infectious diseases; nutrition and mental health; the role of the microbiome in disease; and physical health and diseases. It involves techniques from bench to bedside.

The mental health clinical trials program is an outstanding example of the capacity of the BH-DU partnership. The Barwon Health Director of Research, Prof Peter Vuillermin had the following to say about the alliance; "BH-DU harnesses a formidable mix of setting, skills and vision.

"The IMPACT TRIALS unit has emerged as a world-leader in developing and testing innovative treatments for mental health disorders. This is clearly demonstrated by success at the NHMRC level, an outstanding output of high impact papers, and dedication to seeing their work translated into tangible health outcomes".

The IMPACT TRIALS unit within the IMPACT SRC, Deakin University is working with Barwon Health's Mental Health and Drug and Alcohol Services to recruit for novel therapy trials. These trials are adjunctive to a participant's usual treatment and we have shown this approach to be useful in the past with agents including N-acetylcysteine and minocycline. A/Prof Olivia Dean, Director of IMPACT TRIALS, said "The collaborative research that has been conducted and continues to grow between Deakin University and Barwon Health is beneficial not only to both organisations, but to the Geelong community and mental health research worldwide"

There is an opportunity for people to take part in two adjunctive clinical trials: mangosteen pericarp for bipolar depression and n-acetyl cysteine for methamphetamine dependence.

**Author: Deakin University**





# GENE THERAPY IN AUSTRALIA

A very small change in your DNA is all it takes to develop a life-threatening genetic disease, such as cystic fibrosis, haemophilia, or even cancer. There are over 6000 different genetic diseases, and they affect up to 1 in 20 people. Most are poorly understood and have no specific treatments or cures.

**G**ene therapy is a method of treating or even curing genetic diseases by correcting the cause—by fixing the error in the DNA. With a single injection, microscopic tools can scan the DNA, find the error, and correct it. Thousands of gene therapy clinical trials are happening all over the world, and some are having spectacular results, saving the lives of children and adults with serious genetic diseases.

Right now, scientists at Children's Medical Research Institute (CMRI) are helping to cure previously incurable genetic diseases.

CMRI's gene therapy team have helped to deliver treatments in Australia for diseases such as "boy in the bubble disease" (SCID-X1) and spinal muscular atrophy (SMA). In addition, they've developed a cure for metabolic liver disease, which is entering clinical trials in the UK, and a cure for Propionic Acidemia is in the works which could help children like Charlize Gravina.

No one could tell the Gravina family what was wrong with their newborn twins, Isaac and Charlize, when one became cold and listless soon after they were brought home at four-days-old.

"Then newborn screening results came in," mum, Julie, said. "It confirmed they both had a severe metabolic disorder called Propionic Acidemia."

Propionic Acidemia causes a build-up of acids in the body, which is toxic and leads to brain damage and organ failure.

"It was hard hearing the diagnosis, because the outcomes were very poor. And the management was very difficult."

Isaac received sudden brain damage at nine months old, and despite a liver transplant, tragically passed away from complications before his first birthday.

**“Charlize was like a ticking time bomb,” her mum said. “It was a really hard decision, after we lost Isaac, to decide to transplant Charlize. It was only that her disorder was so severe.”**

Charlize has now had two liver transplants, after her body rejected her first one. The family donated her liver cells to CMRI for gene therapy research.

"I hope in Charlize's lifetime she will receive better treatments and possibly cures. I think we're getting there. We've given Charlize's liver cells to CMRI, and Professor Ian Alexander and his team are working on gene therapy for Propionic Acidemia right now. I think that is just so exciting, given the diagnosis that our children were given, and the outcomes. It's more than you could ever wish for."

Gene therapy is the future of medicine, but much work is needed to apply this technology to more genetic diseases and make it more accessible to patients.

"The biggest bottleneck that slows down translation of





Left Dr Leszek Lisowski (head of VGEF facility) Right Prof Ian Alexander

gene therapy tools to the patient is a global lack of vector manufacturing capacity, which significantly extends the timeline and increases the cost of translational studies,” said Dr Lisowski, who leads the Vector and Genome Engineering Facility (VGEF) at CMRI.

Vectors are microscopic delivery vehicles that carry a healthy copy of a gene to the specific region of the body it needs to go to correct a genetic disease. Gene therapy at CMRI and many other places around the world uses ‘AAV’ vectors. These are based on a harmless virus called Adeno-associated virus. Once a vector to treat a specific condition is perfected in the lab, it needs to be mass produced for clinical trials. Vector ‘manufacturing’ means upscaling production in line with goods manufacturing practice (GMP) to maintain quality control and ensure safety.

“We are actively helping to establish Australia’s first clinical grade vector manufacturing facility, which will help us overcome this bottleneck and give Australian researchers prioritised and cost-effective access to clinical gene therapy reagents. This will facilitate translation of a large number of exciting preclinical programs from bench to bedside.

“Gene therapy, the technology that is currently saving lives and will continue to do so for many decades, is highly underfunded in this country. We should promote development of our own, cutting-edge technologies, and not passively wait until the other markets get saturated and companies start to look at Australia as just another

market to make profit from. Our patients deserve better and many of them simply cannot afford to wait.

“Even as we work toward large scale manufacturing, VGEF is already making an impact. It is the first and currently the only facility of this type in Australia and one of very few globally, making it a highly valuable resource for Australian biomedical research. VGEF serves not only academic researchers in Australia, but also in Europe and the US. The high quality of our services has also been recognised by commercial teams, with VGEF providing reagents to a US based therapeutic company in support of their R&D program in gene therapy targeting paediatric liver disorders.

“Infants who would otherwise have succumbed to spinal muscular atrophy (SMA) are now developing normally with the very real prospect of living full and healthy lives. Individuals with vision impairments owing to retinal disease are seeing more clearly. Those living with haemophilia are being freed from dependency on life-long factor replacement therapy, and cancer patients, previously facing certain death, are being cured with genetically engineered T cells.

“And this is just the beginning.”

**Author: Children's Medical Research Institute (CMRI)**



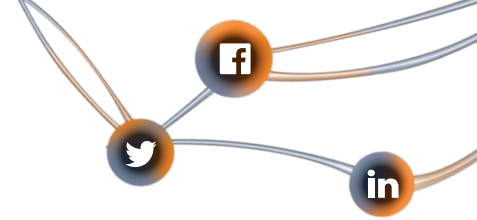
# UNIQUE CLINIKIDS

**A MARRIAGE  
OF RESEARCH  
AND PRACTICE**



A therapy session at CliniKids





**Autism now accounts for 47 per cent of children on the National Disability Insurance Scheme, making it a key health priority for Australia. A model developed by the Telethon Kids Institute marries cutting edge research with clinical practice to offer families a nationally unique clinical research service designed to help kids reach their full potential.**

**A**utism Spectrum disorder (autism) is a neurodevelopmental disorder characterised by difficulties with social and communication skills, and by restricted and repetitive behaviours. These behaviours tend to emerge when a child is between 2 and 6 years of age, but sometimes they are first noticed at a later age. Many individuals with autism also have intellectual disability, difficulties in motor coordination and attention, and physical health issues such as sleep and gastrointestinal disturbances.

Autism research led by Professor Andrew Whitehouse is a key strength of the Telethon Kids Institute, which is now based at the Perth Children's Hospital. The research focuses on developing new interventions and therapies that can help reduce the disability associated with autism, such as language impairment and intellectual disability.

"The goal of health and medical research is not just to understand more about human conditions but also to use these discoveries to improve the health and wellbeing of the community," Professor Whitehouse said.

"The difficulties in translating discovery research to clinical reality are well known, and Telethon Kids has set itself a suite of ambitious strategic goals to measure success, by overcoming these barriers and effecting change to child health in the community."

In response to the discovery-to-clinic 'translation gap', the Institute has developed a new model for conducting clinical research, known as CliniKids.

Launched in January 2019 and located at the Institute's former home in Subiaco, Perth, CliniKids integrates research practice and clinical services for infants and children with developmental disorders.



The clinic – with layout and décor co-designed by parents and carers of children with autism – will support the complex needs of children (and families) with early developmental problems or autism, through early intervention and diagnostic services backed by leading and innovative research.

**“The vision for the clinic is to reduce disability associated with autism and increase wellbeing in the community,” Professor Whitehouse said. “We believe we can do this by creating, researching, translating and disseminating interventions that reduce the disability associated with autism.”**

The model is an Australian first, not only providing families with diagnostic and clinical psychology, and occupational and speech therapy services, but also giving them an important opportunity to be part of novel research.

CliniKids General Manager Gemma Upson said the new service aimed to address the enormous gap between research findings in the field and their translation into clinical practice. One research paper has put the lag between research and practice at 12 years; another a staggering 17 years.

“That’s hugely significant in a child’s life,” Ms Upson said.

“Research is conducted in a very controlled environment and sometimes that can’t be easily translated into the messy real world we live in.

“The CliniKids model has the ability to innately feed clinical expertise into our research and vice versa, so that we can trial interventions in a real-life setting and also evaluate the financial implications.

“Having interventions that are evidence based is very important but if the cost is prohibitive to families and service providers, it may not be widely accepted.



Professor  
Andrew  
Whitehouse

“The clinic is going to bridge that gap – trial the research in a real-life clinical setting, communicate that to the providers, and help educate the community.”

CliniKids currently houses a team of approximately 40 scientists and 10 clinicians, who work together with the parents and carers of children with autism to identify clinical gaps and possible research solutions. The clinical and research teams develop the research ideas together – for example, co-developing a new therapy based on their combination of clinical and scientific expertise. Data from the resulting projects are interpreted by the joint team and then communicated to the broader clinical community.

Professor Whitehouse said CliniKids had a mission to become a centre of excellence for clinical and research training.

“By integrating research projects into the training of medical and allied health students, the hope is that this mindset will provide career-long benefit to their clinical practice,” he said.

One key focus will be exploring early intervention therapies. An estimated two per cent of Australian children have an autism diagnosis, and extensive research has shown that commencing therapy in early childhood will reduce their level of disability.

“Early intervention could be the difference, for example, between a child developing verbal language or remaining unable to communicate verbally,” Professor Whitehouse said.

Although the autism research being carried out by Telethon Kids is regarded as world-leading, Ms Upson said advances had been limited by the absence of a centre like CliniKids, dedicated to new diagnosis and intervention methods in young children.

It’s early days yet and we are busy building our programs and data collection systems, however feedback from families so far has been very positive,” Ms Upson said.

She said families felt reassured that services were provided in a judgement-free atmosphere, and in a modern, purpose-built clinic where everyone was treated with compassion.

“Our families have the confidence too, that our interventions are backed by a skilled research team which uses highly evidence-based interventions,” she said.

**Author: Professor Andrew Whitehouse** is Angela Wright Bennett Professor of Autism Research at the Telethon Kids Institute and Head of the Autism Research Team at The University of Western Australia. He is also Chief Research Officer of the Cooperative Research Centre for Living with Autism (Autism CRC) and Adjunct Professor at Curtin University and Edith Cowan University.

At the Telethon Kids Institute he leads a large team that uses a wide range of methodologies to investigate the early identification and intervention of children with Autism Spectrum Conditions, including molecular genetics, neuroscience, endocrinology, behavioural experiments and clinical trials.





Children participating in a book reading activity at CliniKids



# AVATARS:

## A REVOLUTION IN CYSTIC FIBROSIS TREATMENT

UNSW researchers have developed mini gut and lung 'avatars' that could transform the way clinicians treat individuals with Cystic Fibrosis (CF), the most common life-limiting genetic disease affecting Australian children.

### BREAKTHROUGH DRUGS FOR CYSTIC FIBROSIS TREATMENT

CF is a life-limiting inherited disease linked to more than 2000 different mutations in the CFTR gene. In the mid-20th century people with CF usually died before their 5th birthday. Although there is still no cure for CF, with advances in end-organ symptom care, life expectancy is now close to 35 years in Australia.

Breakthrough drugs such as CFTR modulators have transformed therapeutic options for some CF patients; improving a patient's quality of life as well as their life expectancy to over 50 years. Rather than treating symptoms, modulators directly correct the dysfunctional CFTR protein. However, due to the wide range of CFTR mutations it is impossible to develop a 'one size fits all' treatment.

### NEED FOR PRECISION MEDICINE

Approved modulators, Orkambi®, Symdeko® and Kalydeco® have been developed to correct the more common CFTR mutations, benefiting 60% of patients with CF. But not all patients show clinical improvement. In addition, the remaining 40% of the CF population that have rare CFTR mutations are left without access to treatment.

These modulators come at a tremendous cost to the healthcare system (~\$250,000 per patient per year). New cost-effective methods are needed to identify individuals that are responsive to the modulator drugs.

With no viable animal model to model the vast number of CFTR mutations, one option is to use patient's own tissue as a "CF Avatar" to assess drug responses in the laboratory and translate into clinical practice.

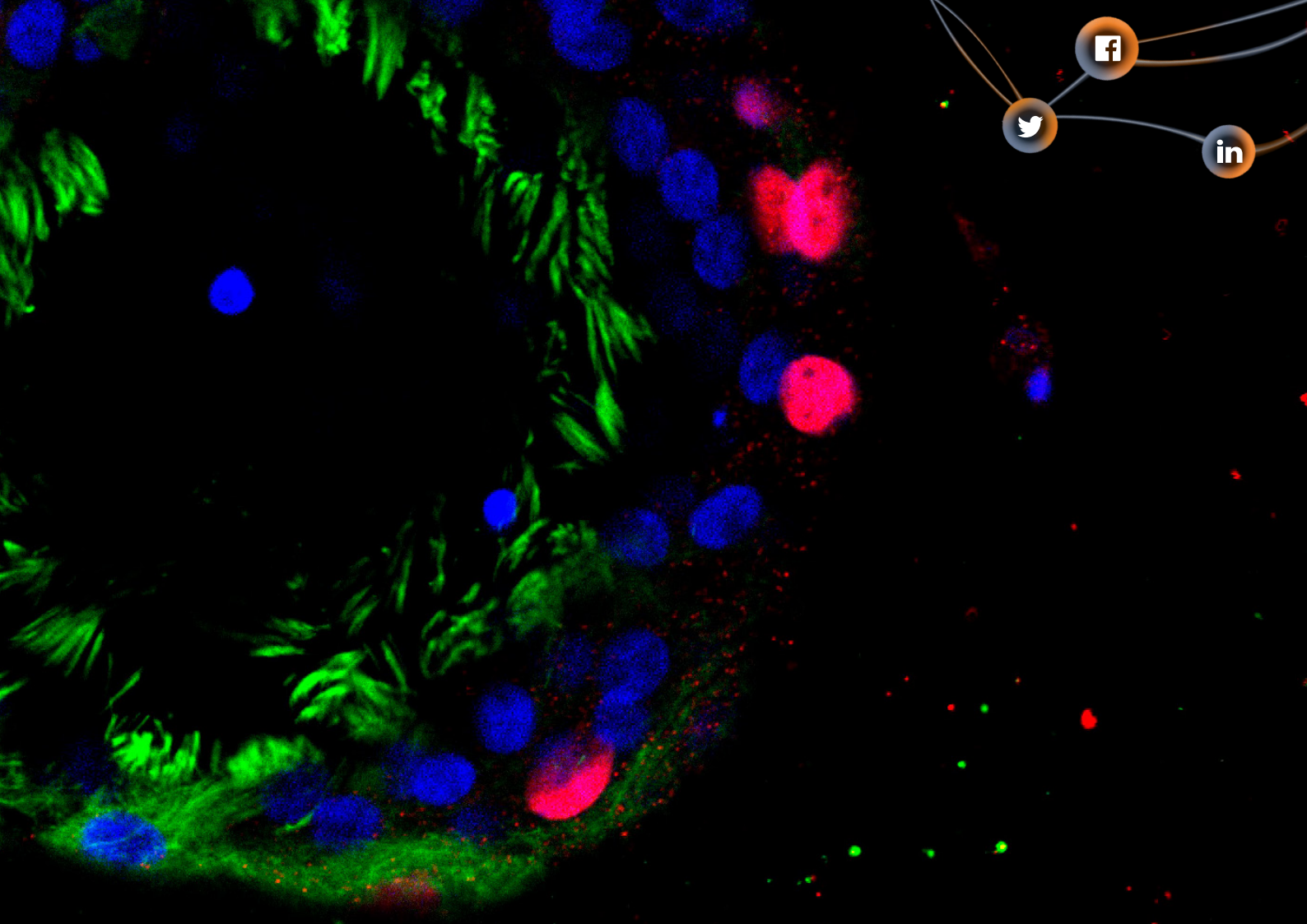
### THE AUSTRALIAN MCF BIOBANK: AN UNPRECEDENTED RESOURCE

Patient derived cell models are essential to basic and translational research in the CF field. Before a new therapy is approved for use in clinical trials, its effectiveness must be demonstrated within cells at the lab bench. Cells isolated directly from respiratory or gut tissue are especially valuable because they are cells from organs relevant to CF disease.

**“Recent breakthroughs in the field of stem-cell biology allow for large-scale expansion of cells, and creation of mini-organs (organoids). Since these organoids are created from the cells of patients with CF, they act like an Avatar for that person. If the drug works on their Avatar, then it will likely work in the patient.**

In most cases, however, it is not feasible to prepare these cells in every CF center or lab as the isolation process can be costly, time-consuming and requires skilled personnel. The culture techniques are not easily transferable between





laboratories. A centralized program operated by an experienced facility is cost-effective and ensures a reliable supply of high-quality research materials.

The molecular and integrative Cystic Fibrosis Biobank (miCF biobank), the first of its kind in Australia, was established through collaboration between UNSW Sydney and the Sydney Children's Hospital Respiratory and Gastroenterology Department. Launched in 2017, the biobank is a national resource of high-quality lung and gut organoids for Australian and International CF researchers. In the past two years the center has biobanked over 150 airway and 50 gut models from children with CF who have been treated at Sydney Children's Hospital.

### HOW WILL A PATIENT'S BIOSPECIMENS CONTRIBUTE TO CF RESEARCH?

At the beginning of 2019 an alliance was established to create a centralised program. The biobank relies on a strong trans-Australian network involving CF clinicians, scientists and their institutions working together with the miCF Research Centre to coordinate tissue procurement from 11 CF clinics across Australia.

Following informed consent, CF respiratory and gut tissue is obtained from the donors at participating sites and provided to the miCF Research Centre. Organoids are then prepared by trained personnel using standardized techniques and quality control measures at UNSW's miCF Research Centre.

The miCF research lab has used the organoids in a functional predictive drug efficacy platform to identify drug responsive from non-responsive individuals. Patients avatars have been tested with various CFTR modulators and those responsive identified, among which three have ultra-rare CFTR mutations. The Avatar technology acts as a crystal ball, attempting to reduce the trial and error in the prescription of medication to targeted CFTR therapy.

The research team is also testing ways to correct the defective CFTR by adding a correct copy of the gene to the cells. These cells serve as an invaluable tool to enhance the current understanding of CF and the translational research efforts that aim to develop new therapeutic agents to fight the disease and shape the future for CF precision medicine in Australia.

**Authors: Dr Shafagh Waters** is the team lead on this project with expertise in bioinformatics skills with stem cell derived organoid culture technology. In 2017 she established the miCF Research Laboratory at UNSW.

**Professor Adam Jaffe** is the John Beveridge Professor of Paediatrics and Head of the School of Women's and Children's Health at UNSW Medicine, UNSW Sydney. He is the co-director of the miCF Research Centre, leading translation of the Avatar Organoid Platform to clinical practice.



# WOMEN BOOST WOMEN ON WIKIPEDIA

Did you know that Wikipedia is the fifth most visited website in the world? And yet, despite its global appeal, women and their achievements are poorly represented among the website's close to 6 million articles.



**O**nly 17% of the people profiled on Wikipedia are women. Not only does this mean that many talented women (and their work) are not getting the recognition they deserve, but it also critically skews perceptions about the contributions that women make to many different endeavours, particularly in health and medical research.

The reasons are difficult to define, however the issue is no doubt influenced by the fact that only 8-16% of the people who actively contribute content to Wikipedia identify as women. Actually, the vast majority of Wikipedia editors are men based in North America.

To help tackle this issue and raise awareness biopharmaceutical company AbbVie and social enterprise Franklin Women joined forces to hold an edit-a-thon event. The event brought together over 40 women working across the health and medical research sector. Together they added over 20,000 words of notability to Wikipedia

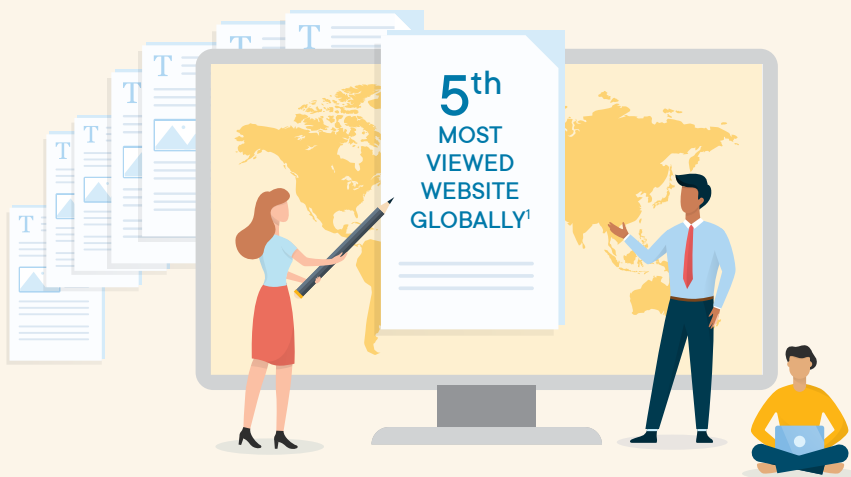
## WANT TO KNOW THE FACTS?

Check out the event infographic (right) summarising the content bias on Wikipedia and how we can all help close the gap!



# Women in STEMM on Wikipedia

CLOSING THE CONTENT GAP



## Wikipedia at a glance

18 billion+  
VIEWS PER MONTH<sup>2</sup>

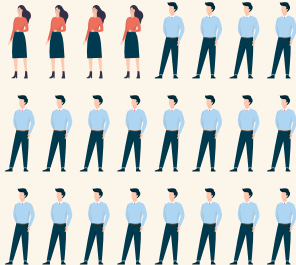
Over  
5,885,259  
ARTICLES<sup>3</sup>

600 NEW ARTICLES  
created per day<sup>3</sup>

## Women on Wiki

1.6 million  
biographies, yet only  
272,000

of them are about women<sup>5</sup>



16%  
WOMEN<sup>4</sup>

## Women in STEMM and Wiki



8,731

Wiki articles about  
WOMEN IN SCIENCE  
& RELATED FIELDS<sup>7</sup>

245

Wiki articles about  
"AUSTRALIAN  
FEMALE  
SCIENTISTS"<sup>7</sup>

## How can you help?

We all can help improve recognition and visibility of notable women and their accomplishments on Wikipedia.

Wikipedia Edit-a-thons are a growing global movement to address content bias.

People around the world are joining forces to create and update articles to recognise notable people from demographics underrepresented on the platform.

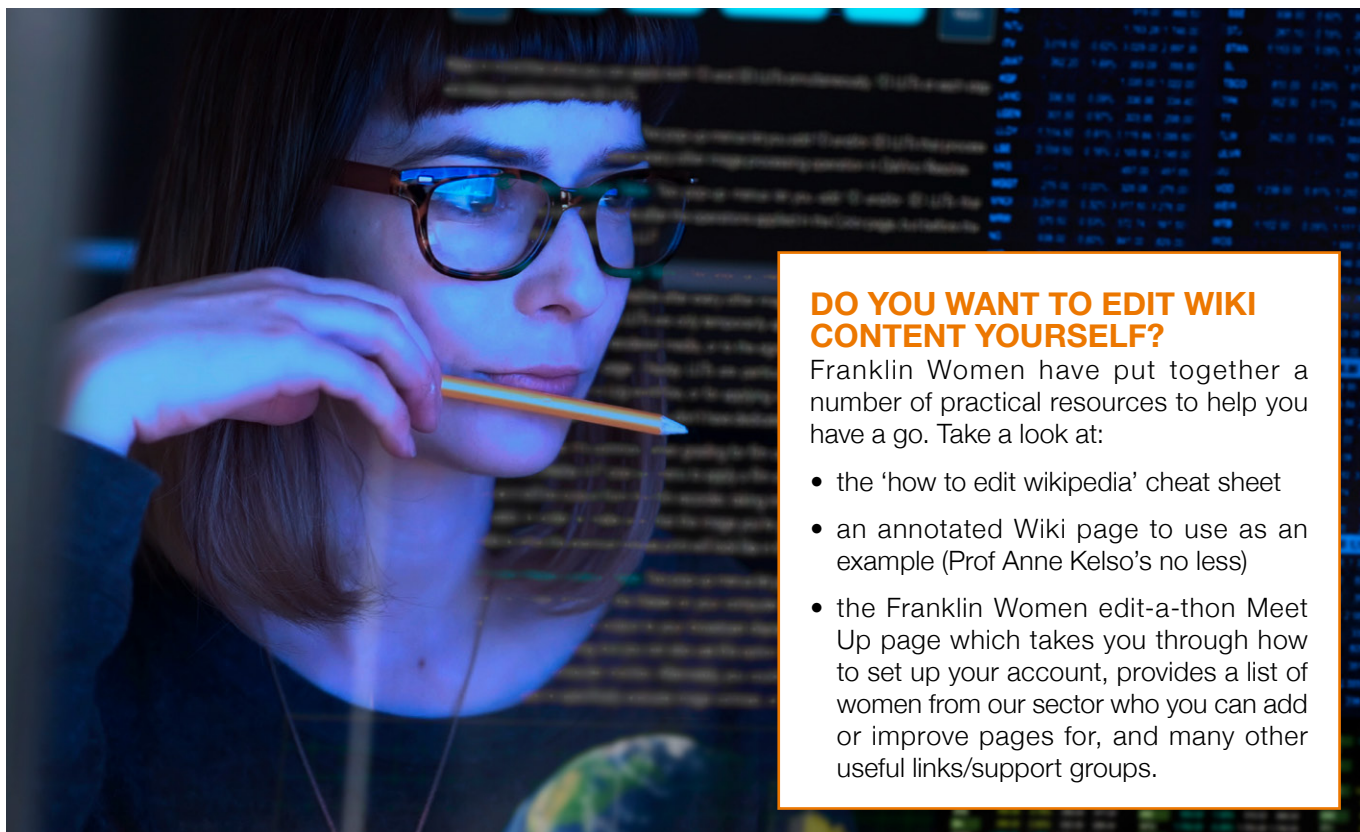


1. Live Wire, *The Top 10 Most Popular Sites of 2019*, 2019. Available at <https://www.lifewire.com/most-popular-sites-3483140> 2. Pew Research Centre, *Wikipedia at 15: Millions of readers in scores of languages*, 2016. Available at <https://www.pewresearch.org/fact-tank/2016/01/14/wikipedia-at-15/> 3. Wikipedia, *Wikipedia: Size of Wikipedia*, 2019. Available at [https://en.wikipedia.org/wiki/Wikipedia:Size\\_of\\_Wikipedia](https://en.wikipedia.org/wiki/Wikipedia:Size_of_Wikipedia) 4. The Lily, *Wikipedia has 1.5 million biographies in English. Only 17 percent are about women*, 2017. Available at <https://medium.com/the-lily/wikipedia-has-1-5-million-biographies-in-english-only-17-percent-are-about-women-57a20fa4f16a> 5. Thrive Global, *Unravelling Wikipedia's Mystery over Women's History*, 2019. Available at <https://medium.com/thrive-global/unravelling-wikipedias-mystery-over-women-s-history-24e863d6735f> 6. Wikipedia, *WikiProject Women scientists*, 2019. Available at [https://en.wikipedia.org/wiki/Wikipedia:WikiProject\\_Women\\_scientists](https://en.wikipedia.org/wiki/Wikipedia:WikiProject_Women_scientists) 7. Wikipedia, *Category: Australian women scientists*, 2018. Available at [https://en.wikipedia.org/wiki/Category:Australian\\_women\\_scientists](https://en.wikipedia.org/wiki/Category:Australian_women_scientists) 8. Interesting Engineering, *New AI helps spot scientists overlooked by Wikipedia and it turns out most are female*, 2018. Available at <https://interestingengineering.com/new-ai-helps-spot-scientists-overlooked-by-wikipedia-and-it-turns-out-most-are-female>

Frankfin Women

abbvie





## DO YOU WANT TO EDIT WIKI CONTENT YOURSELF?

Franklin Women have put together a number of practical resources to help you have a go. Take a look at:

- the 'how to edit wikipedia' cheat sheet
- an annotated Wiki page to use as an example (Prof Anne Kelso's no less)
- the Franklin Women edit-a-thon Meet Up page which takes you through how to set up your account, provides a list of women from our sector who you can add or improve pages for, and many other useful links/support groups.

for women in the medical research sector, including 21 new biographies and edits to 35 existing pages to improve quality and prevent deletion.

Kirsten O'Doherty, General Manager of AbbVie Australia and New Zealand, praised the efforts of the participants and highlighted the importance these impactful, grassroots initiatives.

"As a company with a diverse workforce, AbbVie is committed to ensuring our employees, researchers and industry leaders are recognised for their work regardless of gender or any other demographic."

Events like the Wikipedia Edit-a-thon help to educate people on the contributions of inspiring female researchers throughout history, as well as those pushing the field forward today," she said.

**The event also aimed to equip more women to become Wikipedia editors, through training and support from experienced Wikipedia editors. It is hoped that those who are trained will go on to contribute more content to the website and further increase the notability of women in STEMM.**

AbbVie and Franklin Women plan on hosting more edit-a-thon events in the future and encourage others working in the sector to get behind this important cause.

**Author: AbbVie and Franklin Women**

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#### Clinical Radiology Keynote Speakers:

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Memorial Sloan Kettering Cancer Center, New York, USA

**Dr Andrew J Grainger**  
Leeds Teaching Hospitals and Honorary Clinical Associate Professor University of Leeds, UK

**Dr David Panicek**  
Memorial Sloan Kettering Cancer Center, New York, USA

**Dr David Sacks**  
Reading Hospital, West Reading, Pennsylvania, USA

**Dr Paula Woodward**  
University of Utah, Salt Lake City, Utah, USA

#### Radiation Oncology Keynote Speakers:

**Dr Drew Moghanaki**  
US Department of Veterans Affairs, USA

**Prof Arjun Sahgal**  
University of Toronto, Toronto, Canada

The Royal Australian and New Zealand College of Radiologists



# AUSTRALIA SPEAKS! 2019

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# COLLABORATIVE 'BRAIN IN A DISH' PROJECT TO SEARCH FOR NEW TREATMENTS FOR SANFILIPPO SYNDROME

The Sanfilippo Children's Foundation has secured \$2million of MRFF funding and engaged leading researchers at three partner institutes for a major drug screening project set to fast-track research towards effective treatments for the rare and terminal childhood dementia, Sanfilippo Syndrome.

**R**esearchers from the South Australian Health and Medical Research Institute (SAHMRI), Adelaide's Women's and Children's Hospital and the University of Adelaide – in partnership with the Sanfilippo Children's Foundation – will create patient-specific neuronal cell models that will be used to search for drugs to address Sanfilippo Syndrome.

Associate Professor Kim Hemsley from SAHMRI's Lifelong Health theme says the technology involves taking skin cells from patients, reverse engineering them into induced pluripotent stem cells (iPSCs) and then developing them into neural cells – an individualised representation of the person's brain.

"Each of us reacts differently to a given medication so by using a patient's own cells we can create a targeted, personalised treatment plan," A/Prof Hemsley said.

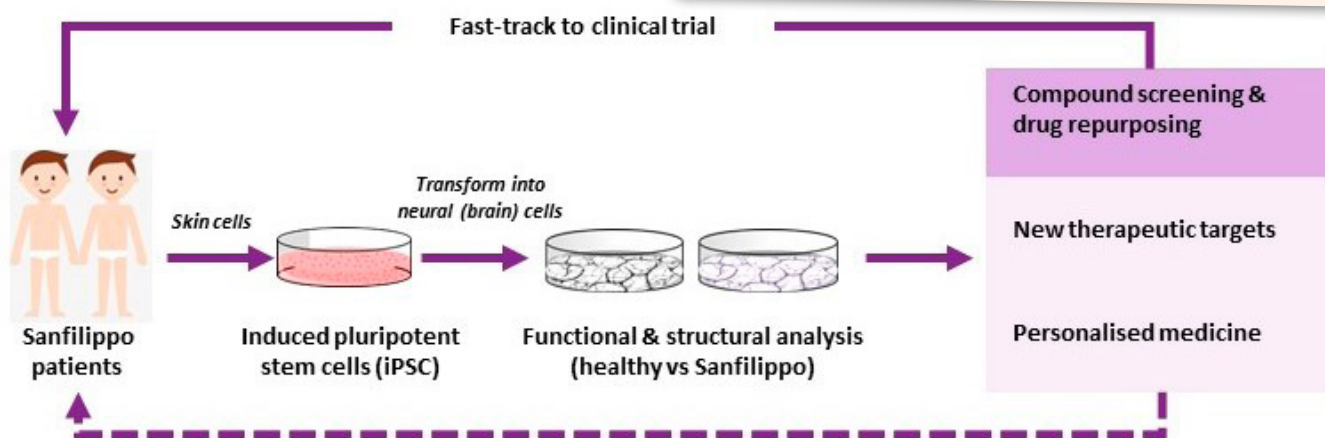
"The other benefit is we can grow a significant number of these 'brains in dishes', meaning we can fast-track the testing of a range of drugs that have already been given safety approval for human use."

**“ Testing using a patient's own cells fast-tracks the research because it enables multiple drug combinations to be trialled rapidly and without risks to the children themselves.”**

They will test many hundreds of different drugs on the cells, initially this will include drugs that are already used for other conditions and could potentially be repurposed for Sanfilippo, but the models will also be useful for testing new therapies being specifically developed for Sanfilippo.

The Sanfilippo Children's Foundation will fund the \$2.5 million project having worked with the researchers to secure \$2 million from the Federal Government's Medical Research Future Fund (MRFF) and chipping in a further \$500,000 of its own funds.

Dr. Nicholas Smith, the head of the Paediatric Neurodegenerative Diseases Research Group University of Adelaide and the Paediatric Neurology Service at the Women's and Children's Hospital in Adelaide, is the project's other Chief Investigator. He welcomes the funding as a demonstration of the Government's commitment to invest in rare disease research.







**Megan Donnell, Executive Director of the Sanfilippo Children's Foundation pictured together with her children, Isla (10) and Jude (8) Donnell, who both have Sanfilippo syndrome, a form of childhood dementia.**

"Sufferers of rare diseases are historically underserved from a research perspective, particularly in paediatrics," Dr Smith said.

"This vital work can not only improve the lives of those suffering with Sanfilippo but has the potential to yield findings with far-reaching clinical influence on many more common neurological diseases."

### STATE OF THE ART

The two-year research project will also involve neurobiologist Dr Cedric Bardy from SAHMRI and Flinders University and Professor Mark Hutchinson from the University of Adelaide.

A variety of techniques will be used by the multidisciplinary team to study the health of the patient-derived neural cell models in comparison to those from healthy participants, and how they respond to compounds. This will include state of the art neuronal anatomy imaging, electrophysiology and transcriptome analysis.

Professor Hutchinson brings a highly innovative aspect to the project – BioPhotonics - a rapidly emerging field with a wide range of applications in clinical medicine and biology. It involves analysing the endogenous fluorescence of biological material, and in this instance, it will allow real-time monitoring of structural and metabolic processes on-going within the neural cells.

### AN UNMET NEED

Sanfilippo Children's Foundation Executive Director Megan Donnell says her organisation's purpose is to ease

the considerable burden on children with Sanfilippo and their families.

"On average, five Australians each year are born with this condition which is currently untreatable, let alone curable."

"We are thrilled to be partnering with the Government and world-leading researchers in Adelaide. We hope this ground-breaking method of personalised drug screening can help improve the quality of life for children battling Sanfilippo.

***"This project is a true demonstration of collaboration with four organisations involved. Alone we can do so little; together we can do so much," Ms Donnell said.***

Sanfilippo Syndrome, also known as Mucopolysaccharidosis (MPS) III, is a serious degenerative condition that causes fatal brain damage. The condition presents in early childhood following an initial period of normal development.

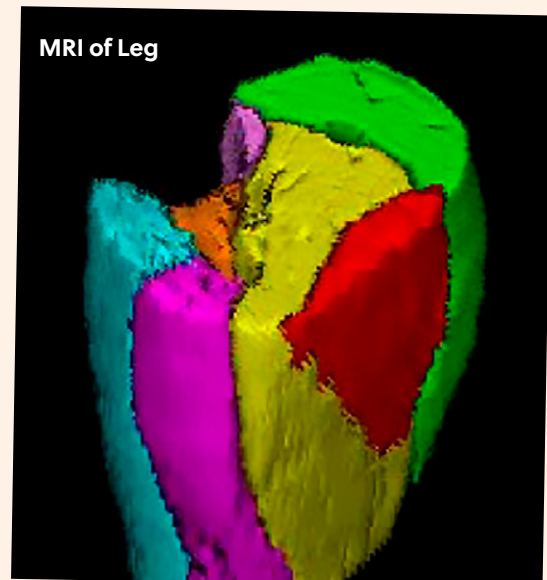
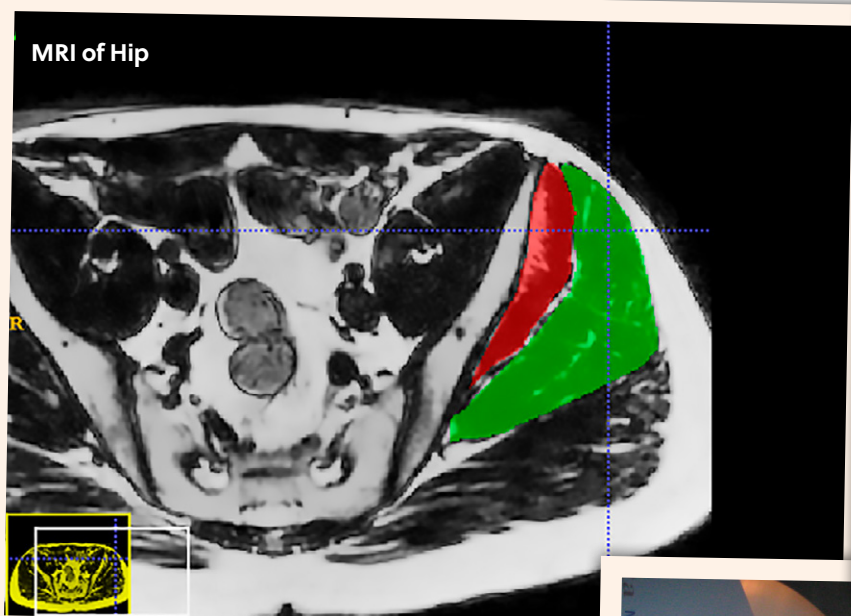
Over time, sufferers experience declining brain function with hyperactive behaviour, disordered sleep, seizures, progressive dementia and loss of mobility. Life-expectancy for children with Sanfilippo is between 12 and 20 years.

**Author: The Sanfilippo Children's Foundation**

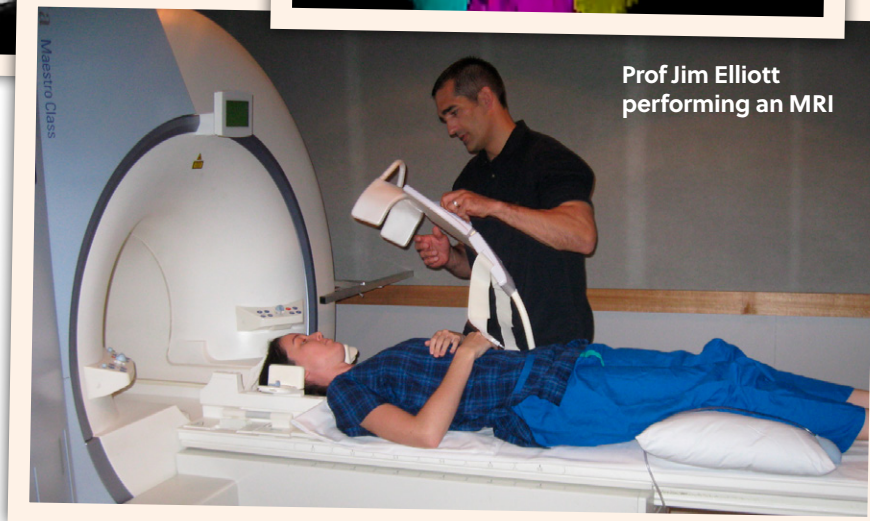


# ARTIFICIAL INTELLIGENCE

## AIDING RESEARCH INTO WHIPLASH



In a technological breakthrough, researchers are using artificial intelligence to determine why some people with whiplash will go on to have long-term changes in their muscles.



**A** team of researchers across the world, led by University of Sydney's Professor Jim Elliott, Dr. Andrew Smith (Regis University) and Dr. Ken Weber (Stanford University), have piloted a new method to quickly and accurately analyse complex muscles traversing the cervical spine to identify those patients at risk of a slower recovery following a whiplash injury.

In the process, they have demonstrated a way to reduce the time it currently takes to analyse the imaging from hours to just seconds, opening the way for the technology to be used widely in radiology research and clinical practice.

The team of researchers has used advanced Magnetic Resonance Imaging (MRI) to quantify specific structural changes – or fat infiltration -- within the muscles of the neck with the aim of identifying those who may go on to suffer long-term whiplash injuries.

But Prof Elliott, of the Kolling Institute of Medical Research, at Royal North Shore Hospital in NSW, said this method was not without challenges as it required patients to undergo an expensive MRI - and not everyone needed an MRI.

The measure further requires an individual to 'draw around muscles'; a process known as manual segmentation.





**Dr Andrew Smith**



**Prof Jim Elliott**



**Dr Ken Webster**

“Drawing circles around the neck muscles of interest, could take the most-experienced researcher up to two hours to complete and that is on a good day,” Prof Elliott said.

“There is a need to enhance, if not automate, the segmentation process, and computers (or deep learning artificial intelligence) is a great way to do so.”

### **WHAT IS DEEP LEARNING?**

Deep learning is a supervised machine learning method in the field of artificial intelligence used to solve complex pattern recognition problems. It is the same technology used by a smart phone to recognise a face or a voice.

Supervised deep learning algorithms can help analyse and interpret medical images by preserving spatial information and greatly reducing the complexity of manually drawing circles on each scan.

This means that scans containing complex anatomy such as MRIs from the neck can be analysed accurately in seconds rather than hours.

“We’ve shown this measure is reliable, clinically friendly and incredibly fast,” Prof Elliott said.

**“ It is the first of its kind in the world to provide objective automatic segmentation of muscle markers for the chronic whiplash condition.**

“Unfortunately, there is no gold-standard diagnostic test to identify such patients as imaging tests have not consistently revealed the biological cause(s) for the wide and varied symptoms of whiplash.

“We have been able to use this new methodology to look at unique patterns identified in the muscles and this may lend itself to the identification of which patients are most susceptible to problems in the long-term.”

**“ It’s now a matter of expanding this available technology to be used in other common, yet enigmatic musculoskeletal conditions such as, low back pain or rotator cuff injuries involving the shoulder.**

Skeletal muscle composition as a biomarker is receiving more attention as advances in MRI technology and supervised deep learning segmentation models permits improved visualisation and rapid quantification of changes to muscle composition. Such work is currently underway and will greatly enhance the information available to radiologists when patients undergo appropriate and clinically warranted imaging for their condition.

If successful, the measure may have major implications for radiology practice and the overall wellbeing of patients with chronic neuro and musculoskeletal conditions.

### **THE COST OF WHIPLASH INJURIES**

Five out of 10 people injured from a motor vehicle crash should expect to fully recover within the first three months. However, the other 50 per cent will continue to have neck-related disability in the long-term and of those, about a quarter will suffer from neck pain, headache, limited mobility, and reports of bodily pain.

Prof Elliott, who is a world leader in whiplash injury research, said while the causes for such chronicity are not completely understood, it is clear that if symptoms persist for six months following injury, it is more likely true than not that the patient could continue to report symptoms in the long-term.

The reported costs of whiplash following a motor vehicle collision are \$950 million across Australia per year.

The study was collaboration between Prof Elliott, Professor of Allied Health at Northern Sydney Local District and University of Sydney and Adjunct Professor in the Feinberg School of Medicine, Department of Physical Therapy and Human Movement Science, Northwestern University; Dr Ken Weber, Systems Neuroscience and Pain Lab, Department of Anaesthesiology, Perioperative and Pain Medicine, Stanford University; Prof Todd Parrish, Feinberg School of Medicine, Northwestern University, and Dr Andrew Smith, School of Physical Therapy, Regis University.

**Authors: Professor Jim Elliott, The Kolling Institute, Dr Andrew Smith, Regis University and Dr. Ken Weber, Standford University.**



# THE LAST WORD



## WHY SHOULD THE PUBLIC FUND RESEARCH?

**A**t some time or another, most health economists have been asked ‘why it is necessary that governments fund medical research?’ At the policy level in Australia, there’s a frequent tension between those who assume that if research is worthwhile, it will find a market, and those who recognise that markets rarely maximise social outcomes.

There’s a plethora of reasons why research will be underfunded in the absence of public support, though there are four which stand out.

First is the issue of information asymmetry. At heart, researchers are researchers, not fundraisers or businesspeople. It’s not only unreasonable to expect them to find their way through finance markets, but it’s a profoundly inefficient distraction from their core business.

Second, research is inherently unpredictable. This matters particularly in the case of preclinical research, where failure rates are understandably very high, and pivots away from the initial hypothesis are common. It simply doesn’t fit any traditional paradigm of a fee for service transaction. It’s also why – in the clinical phase – venture capital is so expensive, because any successful innovation must make sufficient return to cover investments in a substantial proportion of studies which aren’t profitable.

**“ Alongside this, there’s a particular problem for healthcare research of long and expensive timelines. By comparison, information technology and telecommunications research faces nothing like the ethical, safety, efficacy and funding hurdles which slow new medical technologies. As an illustration, a recent estimate of the pre-approval cost of any new pharmaceutical is somewhere between 2-3.6 billion Australian dollars.<sup>1</sup>**

And fourth, we have the Australian problem, which is that we’re a long way from the world’s dominant markets – both for customers, and for finance. Successful research requires both ideas and capital, and these tend to cluster and grow in larger marketplaces – particularly those where innovation-hungry multinationals are based.

These problems aren’t unique to medical and other biotechnology research: in his book *Rockonomics*, the late Princeton economist, Alan Krueger outlines similar characteristics of what are termed superstar markets; where in music, small numbers of performers earn the lion’s share of the money.<sup>2</sup> That said, while it’s similar to health research as a portfolio-based investment market, musicians can rest easy that they don’t need approval from the FDA.

All these issues explain why it would be virtually impossible to fund pre-clinical research commercially, and why we need programs such as the NHMRC and the MRFF. But shouldn’t it be easier to find a market for clinical research, which already has proof of concept?

**“ The answer is that compared to pre-clinical research, it is easier, but there remains a catch. If we leave it to the market, the amount of research which will be funded will still be lower than the amount which is socially desirable.**

The reason for this is that – even with intellectual property regimes as strong as those of Australia – the originator of an invention can never capture all the value of her discovery: there is a free rider effect, as competing firms learn about the new technology; people move from one firm to another and take skill improvements with them; and there is replication in less strict IP markets. So, we still need to subsidise post-campus research in order to deliver the socially optimal share.

By socially optimal, we mean several things. A healthy research program not only employs many people, but it increases competitiveness and exports. Australia has priced itself out of some of our historical manufacturing activities (think cars), so the higher our average level of





skills and education, the better placed we are for such structural adjustment.

And following from the comment on clusters above, we want Australia to grow as a target for the intersection of ideas and capital. The impact of this is not limited to the economic benefits of successful and exportable technologies: the broader research market produces health system efficiencies and other reforms, which are peculiar to our country, and which will never emerge from overseas.

Finally, there's an overriding ethical reason for public funding of research. The reason we fund healthcare in general is not simply economists' preoccupations: keeping people in the workplace; and reducing the cost of chronic disease. We do it even though most of the benefits are privately consumed (people are happier). Research is the driver of better individual lived

experience: it's an incontestable good; and it's one of the best things we can support with tax revenue.

1 Grabowski, Henry G & Hansen, Ronald, "Innovation in the pharmaceutical industry: New estimates of R&D costs", Journal of Health Economics, February 2016, p.31 (US\$ figures converted at AUD=US\$0.7)

2 Krueger, Alan, Rockonomics: A Backstage Tour of What the Music Industry Can Teach Us about Economics and Life, New York, Currency, 2019, p.6

**Author: Alastair Furnival** is a Principal with the Economic Consulting Firm Evaluate and a member of Research Australia and an active member of our Health Economics Roundtables.



The background of the entire page is a teal-colored image showing several petri dishes and a gloved hand, suggesting a laboratory or research setting.

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