

## A word from the CEO

Philanthropy makes a crucial but often overlooked contribution to Australian's health and wellbeing. Professor Ian Fraser's cervical cancer vaccine and Professor Ian Clarke's bionic ear were made possible after years of painstaking research, aided by philanthropic support.

Yet, in Australia, philanthropic support for research is low by international standards.

In 2003, Denis Tracey published *"Giving it Away...in praise of philanthropy"* which is a collection of stories about people who give. He aimed to show that philanthropy should not be the sole preserve of the rich; that it involves time, knowledge, skill and passion in addition to giving money, and that it can be an intensely satisfying, and self reinforcing experience. His book also included valuable commentary on sensitive and contentious questions about why Australians choose not to give, the concept of whether giving is a personal responsibility and the reasons why many people are troubled by the notion that they may have an obligation to "put something back".

Cultural factors that influence philanthropic practice have been a major focus of Research Australia Philanthropy. Having identified the importance of philanthropy in partnering with research institutes, universities and health professionals our goal is to "build the philanthropic pie" by inspiring a new generation of donors, making giving easier and by maximizing the personal rewards that flow as result of the "researcher – donor" experience.

Firstly, we have endeavored to "put our own house in order" through the development of guidelines and strategies to build "good practice" giving. This has included the development of reporting and evaluation frameworks, developing simple and effective communication tools to support the development of meaningful relationships between donors and researchers, and also to give "meaning" to research by highlighting what can be achieved as result of philanthropic donations. This process is vital to build confidence in donors that their contributions will be used wisely and will be applied to an area of research dear to the donor's heart.

Through annual focus group testing and on line surveys, Research Australia has built up a valuable profile of the "average" donor to health and medical research, an understanding of what might influence donor decisions, and what donors believe are the road blocks that limit their capacity or willingness to give to research.

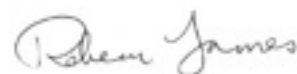
Armed with this knowledge, Research Australia has designed a new public communications campaign, which is being trialled this year and which aims to introduce many Australians who may not yet have taken that first step towards becoming a supporter of Australian research excellence.

*"Cook for a Cure"* is a major national initiative focused on "crowd funding" for health and medical research – using social media to bring together communities of donors and health researchers to support a shared cause. The campaign has been designed to address many of the barriers identified by social commentators, or through quantitative research studies. It aims to develop virtual "giving circles," by harnessing the power of the internet to make giving easy, informed, and rewarding.

A shift in cultural attitudes won't happen overnight, but by building a body of knowledge, expertise and supporting the development of ongoing, trusting relationships between the community and researchers, Research Australia is making a head start.

Now, it is much easier for each of us to get behind our leading Australian researchers. Who knows, your contribution may well lead to the next "big discovery," bringing a cure to countless numbers the world over.

As outgoing CEO, I extend my thanks to Noel Chambers and Nancy Piche for their dedication and commitment to Research Australia and the future of medical research.



Rebecca James  
Chief Executive Officer



“Research Australia Philanthropy’s inaugural conference will bring together local and international experts.

It will offer opportunities to enhance communication, build networks and align expectations between donors, intermediaries, grant makers, government, corporations, community, researchers and research administrators.”

-Rebecca James, Chief Executive



## Philanthropy Conference Bringing together leaders in the sector

“Building a Sustainable Social Investment Strategy for Health and Medical Research”

Australian National Maritime Museum . Sydney . 29-30 August 2011

Register at [www.researchaustraliaphilanthropy.org](http://www.researchaustraliaphilanthropy.org)



# PARTNERING FOR A MALARIA-FREE FUTURE



## WHAT IS MALARIA?

Malaria is an infectious tropical disease spread by the bite of an Anopheles mosquito. The global burden of malaria is borne mainly by poorer, sub-Saharan countries where over 90% of all deaths due to this disease occur.

Most of the victims of malaria continue to be children, pregnant women and people with no access to medicines and health facilities. Of the 780,000 lives lost to malaria each year, 85% are children under 5 years of age - 1 child falls prey to this disease every 45 seconds.

Malaria doesn't just kill, it debilitates both individuals and nations - jobs are lost, school days are lost, productivity is lost, and entire communities remain in its stranglehold. Malaria control consumes more than 40% of national health budgets. This terrible disease perpetuates a cycle of poverty costing more than \$12 billion every year in lost GDP in Africa alone and much more in compromised human potential

[WWW.MMV.ORG](http://WWW.MMV.ORG)

*By Jaya Banerji, Director Advocacy and Communications, Medicines for Malaria Venture*

In these days of multiple demands on philanthropy it is often difficult to decide what to invest in. When a group of scientists got together over 10 years ago they decided to invest in the creation of a small public-private partnership to research and develop new drugs for malaria. Their vision was a world where new and innovative medicines would cure and protect vulnerable populations at risk of malaria. This initial partnership has blossomed into a much larger, successful joint venture involving researchers, foundations, governments, companies and NGOs from around the world.

With a mere \$4 million in seed finance this partnership, Medicines for Malaria Venture (MMV), set to work on achieving its vision, attracting like-minded funders that included the governments of Switzerland, the UK, and the Netherlands, as well as the World Bank and the Rockefeller Foundation.

From these small beginnings MMV has found an impressive group of supporters for their research that now include the Bill and Melinda Gates Foundation, ExxonMobil Foundation, the Wellcome Trust, BHP Billiton, the World Bank, and government aid organisations from the US, the UK, the EU, Ireland, Switzerland, the Netherlands and Spain. MMV is now the only not-for-profit, product development partnership (PDP) dedicated solely to the discovery, development and delivery of new, effective and affordable antimalarial drugs.

Since 2000, when MMV was a pioneering newcomer, working to meet the urgent demand for new drugs for malaria, the once virtually empty pipeline for new antimalarial drugs has now been filled. Today, MMV manages a well-balanced portfolio of more than 50 antimalarial projects in collaboration with more than 130 pharmaceutical, academic and endemic-country partners in 44 countries.

## MMV's partners are its strength

MMV partners with scientists and researchers from academic organisations as well as from the pharmaceutical industry. Industrial partners do not fund MMV's work directly but allow the use of their high-tech facilities, cutting-edge knowledge and years of experience in manufacturing for the research of new antimalarial medicines. Their contribution more than matches the funds MMV receives from its donors, dollar for dollar. Operating as a "virtual R&D company" gives MMV the flexibility and autonomy in terms of allocation and reallocation of resources to rapidly move projects through the pipeline.

After nine years of diligent research, MMV's first success came with the launch of Coartem® Dispersible in January 2009 with partner Novartis. This sweet, cherry-flavoured paediatric antimalarial formulation has brought new hope to countless young malaria sufferers: as of June 2010 around 65 million treatments have been delivered to 35 countries. Two other new medicines have been put through their paces in clinical trials and are now being assessed by the European Medicines Agency.

To the far left of the pipeline, in early-stage discovery, MMV and its partners are identifying and testing hundreds of new molecules and compounds for antimalarial activity. Only a few successful ones will pass the rigorous standards of the pipeline and cross the hurdles of safety, toxicity and efficacy studies to become a new and effective medicine for malaria.

MMV is aligned with the global campaign to eradicate malaria from the planet. To this end, its research and development priorities have been enhanced to seek not only cures and treatments for uncomplicated malaria that meet stringent regulatory standards of quality but also therapies to tackle resistance against current medicines, stop transmission of infection to humans via mosquitoes and cure relapsing malaria, an extremely debilitating form of the disease. In this way, the battle against malaria can take place on all fronts.

An integrated strategy is being used to control malaria that includes the distribution of insecticide-treated bed-nets to malaria-endemic regions and the use of indoor residual spraying of pesticide to kill the malaria parasite-carrying mosquitoes. In spite of these relatively successful strategies, the burden of malaria remains high.

The WHO encourages the use of diagnostics before administration of

**“Africa loses \$12 billion of GDP annually to this disease.”**

treatment in a bid to ensure that only people infected with malaria receive antimalarials. Yet an estimated 250 million cases of malaria slip through the net each year and need urgent treatment with effective medicines.

This is MMV's mandate – to cater to the immediate treatment needs of these millions of people in a manner that goes beyond the development of new medicines alone and includes the delivery of these life-saving drugs to those who need them most. To do this, MMV works with the WHO and other normative bodies to assist in the adoption of new, high quality medicines. It works with industry and in-country partners to explore how to maximise the reach of its products using public and private outlets and innovative delivery

channels. And it works with partners to ensure that the insight gleaned from the field is put to maximum use and the health impact of its new products and the need for new medicines is measured, evaluated and documented.

Malaria is both a cause and a consequence of poverty. The burden of malaria extends beyond impact on human life to impact on national economies. Africa loses \$12 billion of GDP annually due to this disease. MMV recognises that it has set itself a mammoth task. The eradication of malaria will not happen overnight by the efforts of one small PDP alone but will only be achieved by the joint efforts of hundreds of partners working to the same end with the same level of dedication. By investing in the discovery, development and delivery of effective new treatments to control and ultimately eradicate this disease MMV, its partners and its funders will contribute to the benefit of individuals, communities, societies, nations and to the world as a whole.

*Adapted from an article published in the autumn 2010 edition of Effect magazine, ©European Foundation Centre - [www.efc.be](http://www.efc.be)*

# Bupa Health Foundation: Partnerships

*Too often, good ideas never have the chance to make a difference. The Bupa Health Foundation, with its latest partnerships in health research and practice, is trying to put that right.*

The Foundation, which has invested over \$17m in Australian health initiatives, aims to invest in great people with great ideas. And its resources are targeted at the areas of greatest need. Focus areas include chronic disease; wellness; healthy ageing; keeping healthcare affordable; and empowering people in their health. Each of these is reflected in the projects that have been selected in the 2011-12 Bupa Health Foundation Health Awards.



*Above: Mr John Conde, Chairman, Bupa Health Foundation (BHF) Board; Dr Stan Goldstein, BHF Steering Committee, Ms Sonia Dixon, Executive Officer, BHF and Jessica Rowe, MC with the 2010/11 health award winners*

anaesthesia for hip surgery. The objective is to test for incidence of dementia after convincing laboratory evidence suggests an association of anaesthesia with Alzheimer's disease. This could have far reaching ramifications for changes in how people are operated on and how anaesthesia is used – not just in Australia but around the world.

The Foundation also has a long standing interest in chronic pain. This continues with a new project to develop an accredited online educational program for Primary Health Care Professionals to address pain management. This program will align with the national strategy for continuing education and will be of particular importance to regional and rural practitioners who have difficulty accessing quality education.

These are just two of more than sixty partnerships which the Foundation has supported since its launch in 2005. The Foundation hopes that these new partnerships can make a real difference in the health and healthcare of people across Australia.

Dr Christine Bennett is the chair of the Bupa Health Foundation Steering Committee. She believes that the Australian health system is at a tipping point, with new ideas urgently required, especially with a likely squeeze on public sources of funding. She says, "While government provides the bulk of funding for research in Australia, more and more researchers and health innovators are turning to the Foundation to support their vitally important work. The Foundation has launched 11 new partnerships with a total investment of over \$2m for 2011".

One of the latest Foundation partnerships is with St Vincent's Hospital, Melbourne and is examining Alzheimer's disease after anaesthesia. This second phase project uses previous baseline cognitive evaluations in elderly subjects who have received

More information can be found at <http://bupa.com.au/Bupa/about-us/bupa-health-foundation/about>

**Bupa**  
Health Foundation



*Major giving has long been a key plank of medical research funding, with its mix of big ticket equipment, facilities and multi-year program needs. Of course governments are significant 'major givers' but less is known about private giving by the select number of affluent Australians who make substantial donations.*

## Major givers and fundraisers

By Dr Wendy Scaife MFA, FPRIA, Senior Research Fellow, Australian Centre for Not for Profit Studies (ACPNS), Queensland University of Technology

The ACPNS "A Transformational Role" study canvassed nearly 50 major givers and major gift fundraisers through focus groups and interviews, yielding insight about:

- the Australian major giving context
- Australian major givers
- Australian major gift fundraisers/askers
- the organisation/major giver communication

**Why?** The study draws from a key finding in the Giving Australia research (2005) that people who plan their giving donate four times as much as spontaneous donors. Major giving is a prime example of this considered, deliberate and sizeable giving. A body of academic work from other countries has looked at major givers but only limited local data exists. Core signs of potential can be found here though. With currently more than 8,000 individual taxpayers reporting income of a million dollars or more and some 168,000 million plus dollar households, a critical mass of wealth is growing. Analysis of tax deductibility data points to some significant support at these levels and post-code data confirms also that it is flowing from suburbs associated with wealthy Australians. However, giving is not widespread at the million plus and nearby wealth levels. In fact, it is estimated that four out of ten high net worth Australians are giving only negligibly, if at all. Fundraisers in this latest

study pinpointed those with new wealth as particularly untuned to giving.

**Australia's major giving context.** A key finding was the need for a better defined culture of giving in this country, with interviewees airing views that we don't meet overseas giving benchmarks and many people do not even have giving on their radar here. Respondents spoke of low expectation that wealthy people could or would give to the community. A quiet, unheralded code of giving operates for many who wish for various solid reasons to stay 'closeted,' avoiding more asks they are not geared to manage, and staying clear of criticism about flaunting their wealth. Many criticised their peers for not giving, believing people were either too engrossed in the wealth accumulation treadmill or saw that it was

government's role to fill needs and they were giving through their taxes as 'compulsory philanthropy'. The Global Financial Crisis had affected people variously, ranging from not at all to significantly. Some had pushed the pause

button on their giving while others had increased it, seeing greater need. Ten years in, the creation of Private Ancillary Funds was greeted as a boost to the system, enticing many into formal giving who may not have considered it before.

**"The Global Financial Crisis had affected people variously, ranging from not all to significantly."**

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**Messages about major givers.** The study reinforced the sheer power of family moulding for many givers. Even those from humbler beginnings referred to mothers volunteering at schools or Country Women's Association and so on and fathers with service organisation backgrounds. Early examples have impact. Lifestage was predictably important.

"Giving was described very frequently as acting on people's long held values."

Few had time for community involvement while building their business and raising a family and the clear space and opportunity provided by a business sale or nearing retirement saw many enter major giving. As one respondent said, *I'm now 65 and you're getting into the sunset of your life and you really wonder how you can crystallise some of your thoughts.*

Again, predictably, personal values were cited as a huge force triggering major giving and cause destination. Giving was described very frequently as acting on people's long held values. People listed other triggers, including being galvanised by a convincing need that surprised them or a personal connection existing/developed with a cause. A key barrier, akin to overseas studies was how secure people felt in their financial stability, more about attitude than a set figure.

**Messages about major gift fundraisers.** Three qualities emerged as vital in people working in this field: passion for the cause, integrity and robust communication skills. This study spoke with fundraisers with a combined 400+ years of experience in this field. The need for professionalism and for having a role in their broader organisation surfaced often. As one respondent summed it up, *I scrutinise our organisation farther than any funding person of any description ever will.*

**Messages about organisational communication.** Some basic 'hygiene factors' need to be in place before major donors invest in an organisation – and 'invest' is a word they used a lot. Their giving is

about investment more than support. They are searching for outcomes, a return on investment for their socially directed dollars. Perceptions of non-profit efficiency and transparency were not universally high. Donors look to boards but often perceive nonprofits as poorly led, unaccountable and ineffective. Fundraisers see boards as low in understanding of how to resource and support major giving. Investing in major gift seeking capacity often generates high returns respondents report. However, contextually, community understanding of investing in fundraising is low, and anti-spending.

The utterly critical role of the board as guardian and peer to the givers came through vibrantly. So too, the wish to be approached by peers or known likeminded sources in making their 'investment' decision. Current acknowledgment and feedback levels were panned by many donors suggesting the need for more focus here.

The overall picture emerging is of major wealth and major generosity for some but not as an affluent norm. For some, it is a case of major wealth and

"Their giving is about investment more than support."

minor giving. Many wealthy Australians are perceived by their peers to not be giving, or to be giving significantly less than they might readily be able to give. Giving is a choice for those who are involved and is embedded in a life that is financially advantaged. These givers prefer a peer initiated approach at the right time for the right amount, and to an organisation that they can affirm in various ways is worthy. No single major gift decision path can be identified but rather a complex and interrelated set of cultural factors, personal interests, values and peer encounters is in play.

Potential is evident, underpinned by a need to better understand these major supporters. The full study can be accessed at <http://eprints.qut.edu.au/40336/1/40336.pdf>. ■

*Thanks go to study funders, Perpetual, who through the Perpetual Foundation and the EF and SL Gluyas and Edward Corbould Charitable Trusts are gradually consolidating a bank of knowledge on Australian giving.*

# Quality giving; beyondblue's perspective

*It is critical that initiatives for improving community education, prevention, treatment and health care are underpinned by the best available evidence provided through quality research*



It is critical that initiatives for improving community education, prevention, treatment and health care are underpinned by the best available evidence provided through quality research. Therefore, supporting the conduct of quality research to address gaps in knowledge about depression, anxiety and comorbidity is a high priority for *beyondblue: the national depression initiative*. Through its research program, *beyondblue* supports applied and clinical research and the timely translation of research to inform the development of policies and drive enhanced mental health outcomes for all Australians.

*beyondblue* is an initiative of Commonwealth, state and territory governments, established to provide a national focus and leadership about depression and anxiety. The objective of the *beyondblue* research program is to contribute to knowledge-led health improvements through the translation of research into health policy, practitioner training, and the development of information and resources for health practitioners, consumers, carers and their families.

Since 2002, *beyondblue* has invested more than \$37 million to facilitate applied, clinical, and collaborative research, and has plans to invest a further \$10 million over 2011-2012. Research funded by *beyondblue* is assessed through a rigorous peer review process and must comply with the National Health and Medical Research Council guidelines relating to good scientific practice.

Since 2009, following an extensive review of the administration of *beyondblue* research grant programs, several changes were implemented to enhance the efficiency, transparency and consistency for the research grant assessment process. The vital changes to this process included:

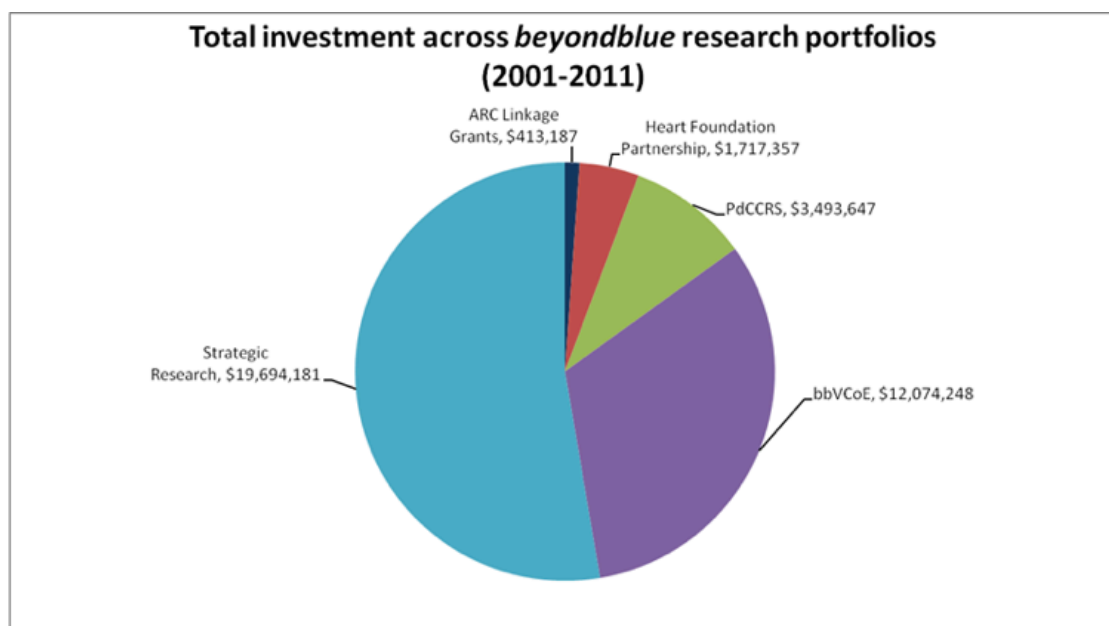
- increased consumer and carer participation
- involvement of Research Australia to facilitate the independent scientific peer review of research grant applications.

Competitive Research grants are allocated through a range of schemes including:

- *beyondblue* National Priority Driven Research program (new in 2011)
- *beyondblue* Victorian Centre of Excellence in Depression and Related Disorders (bbVCoE)
- *beyondblue* Strategic Research Grants
- National Heart Foundation and *beyondblue* Research Partnership
- Priority-driven Collaborative Cancer Research Scheme with Cancer Australia and other funding partners
- ARC Linkage Research Partnerships.

To demonstrate the degree to which the *beyondblue*-research program has contributed to the mental health sector in Australia, a comprehensive independent evaluation of the impact of *beyondblue's* research funding from 2002 to 2010 commenced in 2011. The independent evaluation will help *beyondblue* to identify the key strengths of the research program and how to achieve optimal outcomes.

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*Image 1.1 - Total investment across beyondblue research portfolios*

#### The underlying principles of all research conducted through the *beyondblue* research program

- Mechanisms to apply the research findings into policy and/or practice must be included within the research design.
- Projects must maximise opportunities to collaborate and partner with other organisations and/or researchers of different disciplines.
- Consumers and/or carers must be involved in the planning and conduct of research, and be the beneficiaries of the research outcomes.
- Culturally-inclusive research is encouraged where practicable.
- Research funded by *beyondblue* will be conducted in accordance with the *NHMRC Australian Code for the Responsible Conduct of Research*.
- All research grant applications are rigorously assessed through an independent scientific peer review process.

In 2009, an extensive review was conducted of the systems and process for the assessment of research funding applications in relation to *beyondblue* research grant programs. Since 2010, several changes have been incorporated and implemented to ensure the efficiency, transparency and consistency for research grant assessment. While the assessment process may vary from program to program, the assessment process for each of the programs is multi-staged and incorporates the following processes:

- provision of an online application
- provision of an online grant assessment
- increased involvement of *beyondblue* consumers and carers in the assessment of research grant applications
- development and provision of tailored research assessment training for *beyondblue* consumers and carers
- involvement of the relevant *beyondblue* portfolios in the development of research priorities and the assessment of research funding applications
- involvement of Research Australia in an independent scientific review process.

The standardised application and assessment process for research funding has enabled greater rigor, transparency and consistency.

For more information about *beyondblue* research, go to [www.beyondblue.org.au](http://www.beyondblue.org.au) ■

# Workplace giving and MS Research

Workplace giving is on the increase in Australia. With the emphasis on lots of people donating small amounts to make a big difference, it is a fantastic way to support your favourite charity or medical research institute. There is still enormous untapped potential to grow this stream of giving – which offers a true ‘win win’ situation for all involved - employers, employees and the community:

- **Employees** who choose to donate through payroll, do so in pre-tax dollars and enjoy immediate tax benefits.
- **Employers** report a boost to staff morale and increased retention and attraction of quality talent.
- **Community organisations** experience reduced fundraising and administrative costs.

A recent report by the Australian Charities Fund showed that if just 10% of working Australians made a payroll charity donation of \$5 each week, the Australian community would benefit by over \$260 million each year.

In addition to the benefits outlined above, many employers will match their employees’ donations dollar for dollar. Charities also report increased involvement in volunteering and fundraising activities from employees supporting them through workplace giving.

Earlier this year, MS Research Australia (MSRA) was invited to attend a Volunteering and Workplace Giving Expo hosted by the AMP Foundation. This was a great

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**Australian Charities Fund report**

opportunity for the employees of AMP to meet with the charities their Foundation supports and to find out how they could get more involved.

MSRA’s Relationships and Events Manager, Mandy Lee, met staff and highlighted how they could support MS research through workplace giving or participating in events such as the City 2 Surf – which is also a great way to encourage team bonding and promote a healthy lifestyle!

AMP employees were encouraged to show their support for MS research and the ‘Kiss Goodbye to MS’ campaign by planting their red lips on a specially painted canvas made for the event.

For more information on how you or your company can become involved in workplace giving or fundraising events for MSRA, please contact [info@msra.org.au](mailto:info@msra.org.au).

If you would like more details on setting up a workplace giving program at your organisation, please visit the website for the Australian Taxation Office [www.ato.gov.au](http://www.ato.gov.au) and search for ‘workplace giving’.

AMP employee participating in the MS Research Australia's Kiss Goodbye to MS campaign.



**R E S E A R C H  
A U S T R A L I A**



## [WWW.COOKFORACURE.COM.AU](http://WWW.COOKFORACURE.COM.AU) SUPPORTING AUSTRALIAN RESEARCH PROJECTS

### **Alzheimers Disease and Dementia**

As the baby boomers age, Alzheimer's disease will become more prevalent. Finding a way to delay its onset would help older Australians remain active and healthy as they age.

### **Asthma**

Although current treatments are effective for some asthma sufferers, the response rates are variable, with many patients having symptoms that do not respond to standard treatments.

### **Breast Cancer Survival**

This project will support research to develop a revolutionary technique to enable women to re-grow their own breast tissue after mastectomy.

### **Diabetes**

Researchers at JCSMR are researching new potential drugs that if successful will result in an entirely new approach to preventing and treating diabetes.

### **Epilepsy**

This research holds promise to produce a completely new type of anti-epileptic drug therapy with reduced side effects and a method to reduce seizures while not reducing brain activity when there is not a seizure occurring

### **Food allergy and Asthma in children**

This study will measure the risk of allergy in children aged 10-14 years in their school. The Murdoch Childrens Research Institute will recruit 5000 students to answer a survey on lifestyle factors like diet and allergy history.

### **Heart Disease**

This research project will help develop a promising new treatment, critical in preventing the onset of heart disease before a life-threatening heart attack strikes.

### **Heart Disease and Stroke**

This project aims to make it easier for patients to take their medications by turning four medicines into one "PolyPill".

### **Leukaemia Lymphoma and other blood cancers**

A major focus of this research is to understand and develop new treatments for blood diseases and blood cancers. Some of these, such as leukaemia and lymphoma can strike any of us. Many of these cancers are incurable.

### **Melanoma skin cancer**

The Biospecimen Bank is a collection of blood and tissue samples taken from people diagnosed with melanoma and skin cancer. The biospecimen bank will assist in finding better treatments and ultimately a cure for melanoma.

### **Multiple Sclerosis and Vitamin D study**

This study will give patients three doses of vitamin D to test how effective each dose is at preventing MS in patients at high risk of developing the disease.

### **Ovarian Cancer**

We are seeking to develop a new test to diagnose women with ovarian cancer, which will screen for this deadly disease at a much early stage of its development.

### **Parkinsons Disease**

This research aims to diagnose Parkinson's disease early, before patients develop the classic physical symptoms, and to identify the condition before nerve cell loss has gone too far.

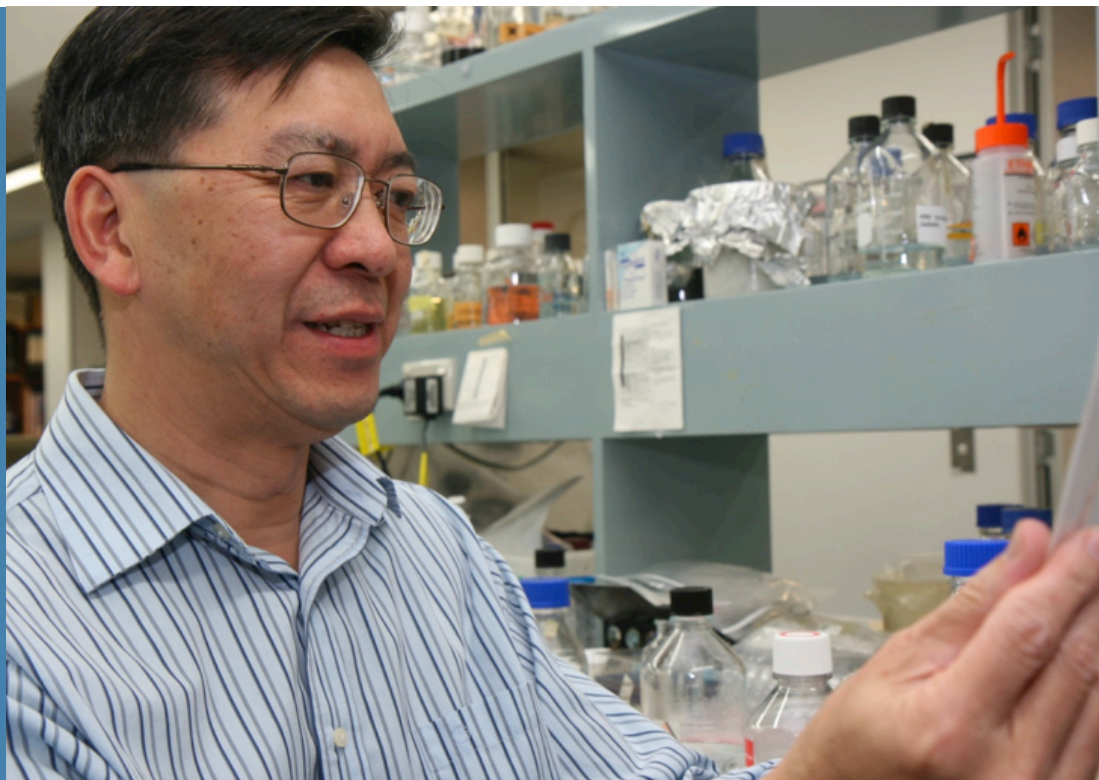
### **Scholarships for young researchers studying Alzheimers and Dementia**

Neuroscience Research Australia hopes to attract a new generation of talented young scientists to build their careers by researching dementia and Alzheimer's disease.

### **Young Mums and Breastfeeding**

Breastfeeding has a significant impact on infant and maternal health, but many women choose not to breastfeed. This study will use a novel approach by studying how young mothers who successfully breastfeed manage to overcome challenges.

Professor Patrick Tam was recently elected as Fellow of the Royal Society (FRS) for his outstanding scientific achievement and career-long contribution to the understanding of mammalian development. FRS is the oldest scientific academy in continuous existence.



## Building blocks for life

*Philanthropy has laid the foundation for my ongoing research into the developmental causes of birth defects and cell-based therapy*

**By Prof Patrick Tam, Head of Embryology Unit and Deputy Director, Children's Medical Research Institute**

I am a medical research scientist and a beneficiary of philanthropy. With it, I have been able to work on some of the most exciting and groundbreaking research projects in developmental biology and genetics. My research program at the Embryology Unit of the Children's Medical Research Institute (CMRI) has been supported by donations from Mr James Fairfax, Kimberly-Clark Australia Pty Ltd, the Sir Norman Gregg Bequest and the Ramaciotti Foundation. Many people in the community may believe medical research is the responsibility of government. However, as the Deputy Director of CMRI, I am acutely aware of just how many of the millions of dollars we need each year to continue our research into cancer, embryo development, gene therapy and neuroscience comes from a wide range of philanthropic individuals, corporations, benefactors, trusts

and foundations and community groups.

One of the key benefits of philanthropic funding compared to government funding lies in its independence and flexibility, enabling medical research institutions to set their own research agendas allowing high quality research to be undertaken over the long term, unaffected by competing agendas and shifting trends of funding preferences. Philanthropic dollars can be deployed readily to support innovative and novel research programs that could lead to new approaches for prevention, treatment and, ultimately, a cure of critical medical conditions.

CMRI's fundraising initiatives such as the national "Jeans for Genes" campaign has been instrumental in strengthening the philanthropic culture in Australia by making it

accessible to people of all walks of life and connecting the community to medical research and enabling donors to interact with and to develop an ongoing relationship with our Institute.

Maintaining a relationship with donors is an important step in strengthening the philanthropic culture in Australia. As donors become involved in supporting a particular cause or research centre such as the CMRI, they become more knowledgeable about the importance of research into early detection, diagnosis and prevention and become valuable advocates for these causes and these research institutions.

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My recent election as Fellow of the Royal Society, the world's oldest scientific academy in continuous existence, marks a pinnacle of my scientific career and brings an enormous sense of fulfilment. This is an honour that I share with present and past members of my research team at CMRI. My scientific accomplishment would not have been possible without the generous support from private donations, philanthropic trusts and foundations, together with research funds provided by CMRI, and the national funding agencies, the NHMRC and the ARC.

CMRI believes that major advances in the prevention of disease will come from research into the fundamental processes of life. With philanthropic support, my team in the Embryology Unit is able to continue to strive for the answers that help us better understand birth defects and genetic diseases.

For the past 28 years I have been researching how the basic body plan of the early mouse embryo takes shape by performing detailed mapping of the ways cells differentiate and move in concert. The map we have produced, often referred to as a "fate map", reveals how cells are assembled together to form the essential building blocks for different parts of the body and how that development is

controlled by signals and genetic switches. With this knowledge we can tell with remarkable precision which parts of the body a specific group of cells will form during development, leading to a deeper understanding of the causes of congenital malformations.

The embryological knowledge is also being applied to aid the discovery of potential drug targets for a neurological disease, Rett syndrome, and to develop strategies to explore the feasibility of cellular and gene therapy for inborn errors of liver metabolism. These projects are collaborations between CMRI, and the Kids Research Institute and Western Sydney Genetics Program of the Children's Hospital at Westmead.

Every child has a right to a healthy future. It is deeply saddening to see kids in hospitals fighting illnesses they cannot comprehend. Our research at CMRI is dedicated to preventing diseases before they occur in our children, or where that is not possible, to developing better treatments.

There is endless opportunity for more innovation in science and medical research and I hope that Australia's philanthropic community continues to grow and provide the support that underwrites much of the progress the medical research sector is able to achieve. ■

**"One of the key benefits of philanthropic funding compared to government funding lies in its independence and flexibility, enabling medical research institutions to set their own research agendas allowing high quality research to be undertaken over the long term, unaffected by competing agendas and shifting trends and funding preferences."**

**Professor Patrick Tam**



**CHILDREN'S  
MEDICAL  
RESEARCH  
INSTITUTE**

#### **About Professor Patrick Tam**

Professor Patrick Tam is the Head of Embryology Research Unit and the Deputy Director of the Children's Medical Research Institute. He is a Senior Principal Research Fellow of the National Health and Medical Research Council of Australia and Professor in the Discipline of Medicine, Sydney Medical School of the University of Sydney.

#### **Fellowships**

Fellowships of the Royal Society, 2011; the Australian Academy of Science, 2008; Society of Biology (UK), 2009; Institute of Biology (UK) 1989

#### **Awards**

Croucher Foundation Fellowship tenable at University of Oxford, 1986; The Symington Memorial Prize of the Anatomical Society of Great Britain and Ireland, 1987; President's Medal of the Australia and New Zealand Society of Cell and Developmental Biology, 2007

#### **Scientific advisory role**

Prof Tam is Chair of Scientific Advisory Board of the Australian Stem Cell Centre; member of scientific advisory boards of ARC Centre of Excellence on Biotechnology Development, Max Planck Institute for Molecular Genetics, Genome Institute of Singapore, RIKEN Centre for Developmental Biology and Cold Spring Harbor Asia Conferences. In addition, Prof Tam is a Member of the Academy of the National Health and Medical Research Council of Australia.

#### **Editorial role**

Prof Tam is Editor of the scientific journal 'Development', and formerly editor of 'International Journal of Developmental Biology', 'Mechanisms of Development', 'Gene Expression Patterns' and 'Anatomy and Embryology'. Prof Tam is also editorial board member of several other journals including 'Developmental Cell' and 'Developmental Biology'.



## CASE STUDY

*Left: Leanne proves that diabetics can still have their cake and eat it too!! She's enjoying a savory Quandong pie.*

# Technology and education make living with Type 1 diabetes easier

*Research led at the Diabetes CCRE at the University of Melbourne is assessing improvements in sugar levels and quality of life through an innovative insulin pump in conjunction with a monitoring device.*

written by Rebecca Scott, University of Melbourne VOICE

Little is known about the daily experience for those living with Type 1 diabetes. Their days are dictated by measuring blood sugar levels, their food intake and energy expenditure. Failure to do so can result in bouts of hypoglycaemia where blood sugar drops too low. This can cause trembling, sweating and palpitations, and in extreme cases slurred speech, lack of coordination, coma and even sudden death.

Those with Type 1 diabetes have an inability to make insulin which regulates blood sugar levels. This means they are unable to transport sugar from the bloodstream into the body's cells where it is used for energy. Type 1 diabetes usually develops in childhood and adolescence and needs lifelong strict management. Type 2 diabetes is the more common form of diabetes and is associated with lifestyle factors such as overnutrition, inappropriate food choices and insufficient exercise. Type 2 diabetes may be managed without insulin.

For over 30 years, Leanne has lived with Type 1 diabetes. She was diagnosed when she was 11 years old when she became very unwell requiring hospitalisation in intensive care. As an adult she says living with the disease is very difficult. "It changes on a daily basis. Everything from stress, emotion, hormones, hot weather, can affect your body. You have to be on the ball, or your day can be a disaster."

Leanne was part of a recent study to assess the improvement in sugar levels and in quality of life after using the latest diabetes management technology. This consisted of an insulin pump which administers insulin under the skin continuously, in conjunction with a Real Time Continuous Glucose Monitoring (RT-CGM) device which measures the patient's sugar levels continuously. Education advising her as to how she should respond to the information about her sugar levels was also provided at the time Leanne and the other patients in the study started using the technology.

Dr David O'Neal from the University's Department of Medicine, based at St Vincent's Hospital said the problem with new technology is that there were no protocols as to how the patient should deal with all the new information. "The technology measures glucose levels in real-time and delivers insulin but it is still left up to the patient to interpret this large amount of information and to determine how they should respond to keep their sugar levels in a healthy range. This response may include eating and/or adjusting the amount of insulin delivered." Results indicate that clinicians and diabetes educators need to educate patients on how to get the most out of these technological advances in diabetes management.

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Dr O'Neal says if a patient is unable to properly assess the data produced by these devices, which provide in-depth information, then the likelihood of error is high. "These errors of judgement continued over time can cause long term health complications," he said. These complications include kidney disease, blindness, amputations, heart disease and stroke.

A test performed on the patient's blood, HbA1c, measures the average blood sugar levels over the previous 3 months. The study found that nearly 50 percent of patients wearing an insulin pump and a real time glucose sensor for 16 weeks, and who were educated early on how to interpret the information provided by the devices, achieved their target glucose level of HbA1c <7.0 compared with only 25 percent of those who had not been educated, but simply provided with the devices and instructed on how to operate and wear them. The education was provided by diabetes nurse educators with sessions lasting about 90 minutes. Improvements were also observed in patient's quality of life with results suggesting a reduction in the impact of diabetes on patient's day to day functioning.

Leanne said being involved in the study and using the pump and sensor gave her the ability to tighten the control on her life. "It just meant I could get on with things without so many complications," she said. "I can't afford the sensor all the time but I do use it to get the balance back when I find my levels rise up into the teens every couple of months," she said.

Dr O'Neal said: "Finger-prick glucose measurements only provide a picture at one single point of the day and at times usually convenient for the patient, which leaves the patient vulnerable for the rest of the day when they have no idea of their blood sugar level." Dr O'Neal added that it is hoped the latest technology will ultimately supplement the traditional finger pricking method of monitoring blood sugar levels "which is like driving blind and then opening your eyes for a few minutes for a few times each day."

Unfortunately due to cost, the technology is not readily available to all Type 1 diabetes patients. "It is

hoped that as the technology evolves, so too will health policy enabling more access to those who will benefit," he said.

Professor Jim Best who leads the NHMRC-funded Diabetes CCRE, says management of Type 1 diabetes is a complex and demanding task. "The Diabetes CCRE has brought together a group of clinical research investigators with extensive experience in diabetes management, who are seeking ways to improve the lives of people with diabetes. The work of Dr David O'Neal and the research team and collaborators, demonstrate translation of new technologies into clinical practice. These developments offer hope of a brighter future for people carrying the significant burden of Type 1 diabetes."

For more information visit

[www.diabetesccre.unimelb.edu.au](http://www.diabetesccre.unimelb.edu.au) ■

*This is a shortened version of an article written by Rebecca Scott which appeared in University of Melbourne VOICE, vol. 6, no. 11*



Professor Jeffrey Lipman (foreground) and Dr Jason Roberts (background) in the Intensive Care Unit at the Royal Brisbane Women's Hospital



## Building blocks for life

### *Bali bombings give rise to the Burns Trauma and Critical Care Centre*

By Dr Sia Athanasas, Research Manager, Burns Trauma and Critical Care Centre

In 2002, the devastation and tragedy of the Bali bombings focused national and international attention on burns victims. The outstanding response from the critical care and burns staff of the Royal Brisbane & Women's Hospital (RBWH) and The University of Queensland (UQ) highlighted the skill and expertise possessed in this area. Nonetheless, the event emphasized that there was a critical need to improve the treatment and outcomes of burns and critically ill patients.

Since the Research Centre was formed, there has been innovative and significant research related to initial management such as optimal antibiotic dosing and fluid resuscitation, a more accurate diagnosis of infection and management of inhalation injury. These findings equipped the staff to better treat and save the

lives of many of the victims of the bombings who otherwise would have succumbed to infections and organ failure. There has been further ongoing research related to optimal nutrition, psychological health, prevention of scarring, pain and itch, and the role of exercise to ensure that the ongoing quality of life is worthwhile. Our strong research background in these treatments has been fundamental in saving and optimizing the lives of burns victims. Many of the clinical staff have enrolled in higher degrees and become involved in clinical research further building the skills and capacitance on this important area.

The Burns Trauma and Critical Care Research Centre (BTCCRC) was established to further advance the level of expert treatment and care given to burns and critically ill patients through world-class, research-based, clinical practice.

Our research addresses health issues of critically ill patients at the coal face of critical care, the Emergency Department (ED), through the Intensive Care and Burns Units to recovery, the Rehabilitation phase.

Initially a collaborative venture between the RBWH Burns, Intensive Care and Anaesthesia Units and UQ, the Department of Emergency Medicine (DEM) was incorporated into BTCCRC in 2008. BTCCRC is headed by Director, Professor Jeffrey Lipman and chaired by Research Fellow Dr Jennifer Paratz.

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### Research Activities

Our clinical research is based on a solid foundation of multidisciplinary collaboration between intensivists, burns surgeons, anaesthetists, cardiologists, neurosurgeons, emergency physicians, pharmacists, scientists, physiologists, nutritionists, allied health therapists and intensive care nurses.

Our laboratory research is closely allied with our clinical research to ensure translation from bench to bedside. The research within the centre is divided up into five core disciplines, each with their own research agenda -:

- Burns — the overall treatment, management and outcomes of burns patients.
- Antibiotic therapy encompassing dosing, distribution and pharmacokinetics in burns and non-burns critically ill patients.
- Treatment, management and outcomes of non-burns critically ill patients.
- Anaesthesia—modeling of evaluating new procedures for anaesthetising critically ill patients.
- Emergency Medicine—improving outcomes and evaluating new processes for treating patients, including trauma patients, in the Emergency Department.

### Bioanalytical and Skin Culturing Facilities

The BTCCRC possesses bioanalytical capabilities that are out of the reach of most ICU's worldwide. For over a decade, we have been measuring drug levels in plasma, ultrafiltrate, urine and microdialysate by various chromatographic techniques. With access to an Applied Biosystems API2000 Liquid Chromatography-Mass Spectrometer, analysis of smaller and less concentrated samples is now possible. This, en masse with the up and coming Skin Culturing Facility at the RBWH which will produce

sheets of skin for grafting onto burns victims, will result in a major leap forward for our research into the innovative treatment and management of critically ill and burns patients.

Not only will innovative treatments emanate from strong research culture and environment, but research aids in building capacity for our medical and scientific workforce, bringing professional excellence to world-class stature. As medical researchers we have the opportunity and capability to change policy and practice for the good of patients, not only at a national level but also globally. ■



### Aims

*The main aims of our research centre are to:*

- Improve both the survival and outcome of patients by conducting high quality research in the area of Burns, Trauma, Critical Care, Emergency Medicine and Anaesthesia in general.
- Provide a research-driven evidence base that informs clinical practice and policy in Burns, Trauma, Critical Care, Emergency Medicine and Anaesthesia.
- Establish local, national and international collaboration in these clinical areas thus increasing research opportunities and potential.
- Enhance the research training and knowledge base of higher degree students and staff in the above clinical areas.



Above: The Wicking Dementia Research & Education Centre Team

## Wicking Dementia Centre addresses severe community need

*Three years since inception, the Wicking Dementia Centre at the University of Tasmania (UTAS) is already attracting millions in competitive grants and other income as a result of philanthropic funding.*

**By: Di Carter, Wicking Dementia Centre Executive Officer (Strategic Operations)**

The Wicking Dementia Research and Education Centre (Wicking Dementia Centre) is based at the Menzies Research Institute Tasmania, an institute of the University of Tasmania (UTAS). The Wicking Dementia Centre's mission is to prepare Tasmania, and thereby Australia, for the rapid increase in numbers of people with dementia.

In 2010 an estimated 1.1 per cent of the Australian population live with dementia (~245,000 persons) and it is estimated that by 2050, 2.8 per cent of the Australian population will suffer from dementia (~1.13 million persons).

The Wicking Dementia Centre is the brainchild of Professor James Vickers, Head of School of Medicine UTAS, and Professor of Aged Care Nursing Andrew Robinson, School of Nursing & Midwifery UTAS, and was seeded in late 2007 by the JO & JR Wicking Trust (managed by ANZ Trustees).

Three years on and the Wicking Dementia Centre continues to consolidate its research program through four key areas: dementia health services development in community care, residential aged

care and acute care; investigating the biological basis of dementia; exploring the trajectory of dementia; and education and community engagement (through a program of seminars and an annual research school).

One of the unique aspects of the Wicking Dementia Centre is that under the guidance of our two internationally renowned Co-Directors, the neuroscientist team led by Senior Research Fellow, Dr Tracey Dickson, and the social science arm headed by Senior Research Fellow, Dr Christine Stirling, continue to successfully create knowledge in their own areas of expertise, and to cross fertilise ideas and experiences.

This dynamic relationship creates a thought-provoking collegial environment enabling traditional boundaries to be extended with continual exploration of what it means to be, for instance, a carer of a person with dementia or what is actually happening at the level of neurones in the brain.

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This dynamic relationship creates a thought-provoking collegial environment enabling traditional boundaries to be extended with continual exploration of what it means to be, for instance, a carer of a person with dementia or what is actually happening at the level of neurones in the brain. This backdrop is also energised by our sixteen PhD candidates and an Honours student, who are encouraged to publish articles and present their research at international and national conferences.

Dr Sharon Andrews, NHMRC TRIP Fellow (Translating Research into Practice) at the Wicking Dementia Centre works on palliative care practices of aged care staff in nursing homes and was successful in receiving a large grant from the Department of Health and Ageing (DoHA) to open up dementia care dialogues. This research, based in Hobart and Melbourne, with Australian Catholic University collaborator Associate Professor Fran McNerny, is looking at the effectiveness of placing a highly trained Palliative Care Resource Nurse in a nursing home as the central care point for a person with dementia and also the use of a discussion tool to facilitate family caregiver dialogues about dementia.

The Wicking Dementia Centre also works with Associate Professor Chris Toye at Curtin University, WA and Professor Michael Ashby of the Department of Health and Human Services Tasmania currently running another DoHA funded grant based in Launceston and Perth, exploring the Community of Practice of care for people with dementia.

Dr Mathew Summers is a Chief Investigator on the Tasmanian Healthy Brain Project. The project explores the effects on brain plasticity on 50 -70 year olds who choose to go to university to study. Does tertiary education boost cognitive reserve? Does it reduce the risk or delay the onset of Alzheimer's Dementia? Over 250 students are now enrolled at the University of Tasmania, each volunteering to undergo annual cognitive assessments for, initially, a five-year period. The impact of delaying Alzheimer's Disease onset by five months would create savings of \$6.6 billion in health costs by 2040; and delaying Alzheimer's Disease onset by five years would represent a \$67.5 billion saving in health costs by 2040.

Collaborations between the Wicking Dementia Centre and health science researchers extend

globally, with, for example, Dr Karen Ritchie in the French National Institute of Health and Medical Research (Inserm) and Dr Michael Valenzuela of the University of New South Wales. The Wicking Dementia Centre is also building its research capacity across many disciplines of UTAS, with Research Associates in the School of Psychology with Dr Jenn Scott, and the School of Architecture and Design with Professor Roger Fay. In addition, Tasmanian allied health professionals also perform an important role in dementia research with Senior Geriatrician Dr Jane Tolman, Director of DHHS Tasmanian Clinical Networks Wendy Quinn, and Debbie Slater, CEO Alzheimer's Australia Tasmania amongst many others.

As a direct consequence of the successful philanthropy funding, UTAS central funding was acquired and, in the three years since inception, the Wicking Dementia Centre has also attracted over \$6 million dollars in competitive grants and other income. The generation of \$6.9 million from the \$1.5million gift reveals that the philanthropy dollar has, thus far, generated \$4.60 value-added investment.

The Wicking Dementia Centre is indebted to the JO & JR Wicking Trust, managed by ANZ Trustees, and we thank them for their support. They have enabled the creation of a hub for dementia research excellence in Hobart, supporting a number of academic and professional staff towards solving the puzzle of dementia, which will have impact nationwide. ■

## Want to make a difference to health and medical research?

Research Australia provides strategic guidance, tools and resources to support effective partnerships between health & medical research and philanthropy.

We can help you:

- Develop effective giving strategies that make a difference.
- Find quality research projects that meet your giving needs.
- Review research projects using our expert advisory panel services including scientific review.

For further information please contact Dr. Noel Chambers (03) 9662 9366

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



Research Australia's proprietary tools, experience and expertise can help you identify, review and maintain research projects that meet your giving needs. Our personal advisory service, offers confidential, independent and transparent governance procedures linking you with Australia's leading scientists.

Our suite of linkage services can help you by:

- Developing effective giving strategies that make a difference.
- Identifying quality research projects that meet your giving needs.
- Reviewing research projects using our advisory panel whose considerations include scientific merit and community benefit.
- Providing recommendations against alternative research options to assist decision making.
- Assisting with your acquittal processes.
- Delivering administrative efficiencies to grant making programs conducted by established Trusts and Foundations.
- Providing independent and transparent processes to assist in delivering best practice solutions.
- Expanding your networks.

### Our services

#### RAP Linkage Program

Our RAP linkage program is operated through a centrally coordinated unit within Research Australia preserving anonymity for philanthropists and researchers.

#### Advisory Panel

Research Australia has established an advisory panel to provide expert review of research projects including scientific merit and community benefit. This service is part of the linkage program but may be accessed separately where a grant maker has independently identified a short list of projects for potential funding.

#### Research Register

The Research Register is managed by Research Australia to facilitate linkages between grant seekers, grant makers and philanthropic service providers. The register is not publicly available and assists Research Australia to identify potential research programs that match the criteria provided by grant makers.

#### Administration

Research Australia can assist organisations with the management of their grant making administration by undertaking this role in a contractual capacity. In particular, this service provides cost savings to smaller organisations where the size of gifts may not justify the resources to manage them in-house.

#### Toolkit

The Research Australia Philanthropy Toolkit: Giving to Health & Medical Research is an educational resource for grant makers, grant seekers, service providers, corporate entities and the community. Copies will be available for purchase by non members. A free copy of this toolkit is available to our members upon request.

#### Membership

Research Australia's Medallion members and above are entitled to a discount on our linkage program services. They have access to a member's only area on the Research Australia website and receive invitations to participate in Health & Medical Research Philanthropic roundtables.

**For further information please visit our website [www.researchaustralia.org](http://www.researchaustralia.org) or call 03 9662 9366.**

**Dr. Noel Chambers: Director Philanthropy**  
**Ms. Nancy Piche: Project Manager**