



Australian Philanthropy



Winter 2010, Issue 76



Health, wellbeing and medical research philanthropy

■ The health risks
of climate change

■ Sir Gustav Nossal
on research

■ Understanding
community wellbeing

**Australian Philanthropy is the journal
of Philanthropy Australia Inc.**

Philanthropy Australia is the national peak body for philanthropy and is a not-for-profit membership organisation. Our Members are trusts and foundations, families and individuals who want to make a difference through their own philanthropy and encourage others to become philanthropists.

Our vision
A giving and caring nation.

Our mission
To represent, grow and inspire an effective and robust philanthropic sector for the community.

Philanthropy
The planned and structured giving of money, time, information, goods and services, voice and influence to improve the wellbeing of humanity and the community.

Philanthropic sector
Trusts, foundations, organisations, families and individuals who engage in philanthropy.

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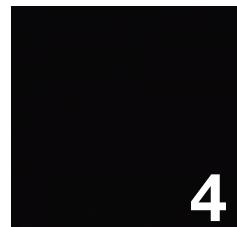
Professor Hugh Taylor of The University of Melbourne's Indigenous Eye Health Program conducts an eye health check on a young man. In 2008 The Ian Potter Foundation provided a grant of \$1 million over five years to help the team tackle the widespread incidence of trachoma, a preventable and treatable eye disease that affects many Indigenous communities. Since then Professor Taylor has gone on to secure major Government funding to help redress the inequity of Indigenous eye health in Australia. Read about this project on page 17.



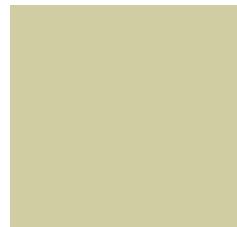
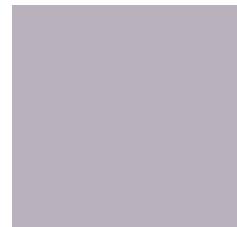
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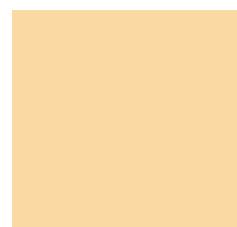
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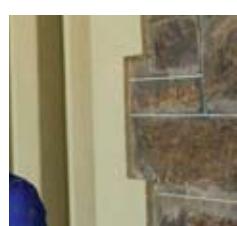
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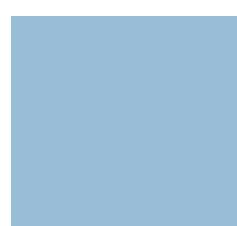
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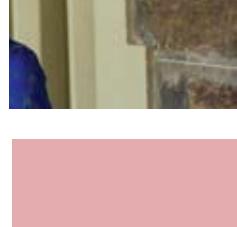
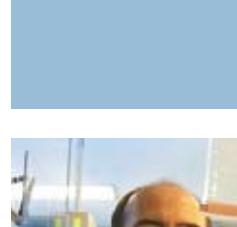


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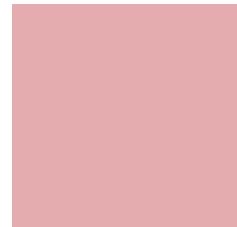


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From the President



Since the dawning of charity, the contribution of healthcare and medicine to individual and community wellbeing has changed dramatically, and so too has its position within philanthropy.

In the preamble to the Statute of Queen Elizabeth of 1601, upon which our definition of charity is based, the only reference to health is 'maintenance of sick and maimed soldiers and mariners'. In the Macnaghten judgement of 1891, which established the four heads of charity, health is again not explicitly recognised, although it and medical research comfortably fit within 'other purposes beneficial to the community'.

So health and medical science have had to build a place within philanthropy. Contemporaneously, philanthropy has also been the catalyst for new research,

the development of best practice and increasing government engagement. The consequences of the evolving nexus between health research, philanthropy and government policies, which have had global, national and local dimensions, has been profoundly positive.

In Australia over the last 40 years the life expectancy of women has increased from 74 years to 84 years and for men from 67 years to 79 years. This reflects many factors including breakthroughs in medical research, new advanced drug treatments, an improved Australian health system and more comprehensive approaches to improved health, based on social determinants. Philanthropy has played a part in all of these developments.

However, today there is still more to be done to foster medical research and improve community health. In particular there is still a role for philanthropy to act as a catalyst for change, to provide seed funding, to identify areas of high need that are being missed by government or industry funding sources, and to ensure that the inter-relationships between

medicine and other determinants of health are better understood.

In many cases it is personal or family experience that attracts the deep commitment and engagement of philanthropists to medical research. In my case it is developmental medicine, which has never attracted sufficient funds to identify the causes of disability or to improve treatments for people with disability, despite the fact that disability is life long.

Over time, community wellbeing, health research and philanthropy will all be the richer as more people are attracted to supporting those aspects of health with which they are personally connected and passionately committed to making a difference.

Bruce Bonyhady AM, President

From the CEO



Australian medical researchers, according to 2006 Australian of the Year Professor Ian Frazer, "punch well above their weight."

"The estimate is that for every dollar you put into medical research, \$7 is returned to the community in investment return, so the argument both financial and social for good medical research is overwhelming."

Philanthropy has long funded health initiatives and medical research, with profound impacts – from developing vaccines to the Cochlear implant. In 1916 a small portion of The Walter and Eliza Hall Trust's annual income was set aside to found and support an institute of medical research in Melbourne, the first in Australia.

This year Professor Patrick McGorry is Australian of the Year, recognising his pioneering work in improving mental health in adolescents and young adults. We are delighted that Professor McGorry will speak at the forthcoming **Philanthropy Australia Conference 2010: Philanthropy at the tipping point?**, and that he will be introduced by Andrew Brookes from Colonial Foundation Trust, a long term funding partner of the Orygen Youth Health Centre (profiled in *Australian Philanthropy Issue 74*).

Today philanthropic funding to medical research has increased substantially, in addition to a rise in funding for health programs. For instance, Public Ancillary Funds have increased their funding from 2005-2006 levels, which saw \$2,001 million go to research (medical and other) and \$5,720 million to health. In 2007-2008 \$11,285 million went to research and \$8,024 million to health (ACPNS – QUT Current Issues Sheet 2010/1).

However Australian philanthropic giving to health and medical research is still at a relatively low level by international standards. In the US, Canada, and the UK, philanthropy contributes 25 per cent to 30 per cent of funding from all sources for health and medical research, whereas in Australia it is estimated to be only 12 per cent of total funding.

The recent remarkable donation of \$2 million – his first year's salary – by the new National Broadband Network boss Mike Quigley to aid research into brain diseases and stroke rehabilitation, is a milestone gift. The doyen in this field, however, has to be the remarkable Chuck Feeney through The Atlantic Philanthropies, whose multiple gifts over the past decade to medical research in Australia are in the hundreds of millions, and have generated much more.

Gina Anderson, CEO

Charles Goode AC appointed Life Member



At the Annual General Meeting in April 2010, Charles Goode AC was appointed an Honorary Life Member of Philanthropy Australia.

Charles is the longstanding Chairman of The Ian Potter Foundation. After a distinguished career at Potter Partners, including as its Senior Partner, he has had a long career as a prominent Director and Chairman of major public companies, as well as board and committee appointments at a large number of charitable and health-related organisations. The Council and Members of Philanthropy Australia would like to thank Charles for the tremendous support Philanthropy Australia has received from both ANZ and Charles personally.

Philanthropy Australia Membership Survey

Thank you to the 96 Full Members who completed the 2010 Membership Survey. Among the survey findings:

- 75 per cent of respondents indicated that their organisation's biggest challenge was evaluating the impact of their grantmaking.
- 67 per cent of respondents fund Australia wide; 23 per cent are limited to funding in Victoria only; and a surprising 16.5 per cent fund international projects.

We are very appreciative that so many of you took the time to fill out the survey, particularly those who offered thoughtful suggestions and comments, and will soon be producing a survey report.

Award for The Myer Foundation and Sidney Myer Fund

The Myer Foundation and Sidney Myer Fund have been named as this year's recipient of the prestigious International Funders for Indigenous Peoples' Award. The award is given annually, to an individual or institutional donor that exemplifies leadership in Indigenous Philanthropy. This is the first time the award has been presented to an organisation outside of North America.

According to International Funders for Indigenous Peoples (IFIP), The Myer Foundation and Sidney Myer Fund have been honoured with the 2010 IFIP Award in recognition of their "outstanding progress towards improving Indigenous education and wellbeing and support for better natural resource management in Australia."

New bio-technology investment

Andrew Forrest has teamed up with former Australian of the Year and co-founder of the cervical cancer vaccine Professor Ian Frazer to invest in a vaccines technology business chasing treatments for a range of diseases such as influenza, hepatitis C and cancer. Allied Medical, an unlisted public company controlled by the Fortescue Metals chief executive, has agreed to invest \$3 million in Brisbane-based junior biotechnology company Coridon. Coridon, which was founded in 2000 for the purpose of developing DNA therapies for the prevention and treatment of viral infections, is chaired by Professor Frazer and is backed by the Liberman family, and UniQuest, the University of Queensland's main commercialisation company.

Honours List

Congratulations to Philanthropy Australia president Bruce Bonyhady who was honoured with an AM (Member in the General Division of the Order of Australia) in this year's Queen's Birthday Honours list.

We would like to congratulate all our Members who were named in the 2010 list:

- The Hon. Steve Bracks, Chair, Deakin Foundation (AC)
- Harold Mitchell, Founder, Harold Mitchell Foundation (AC)
- Elizabeth Proust, Patron, Mary McKillop Foundation (AO)
- Bruce Bonyhady, President, Philanthropy Australia (AM)
- Martin Copley, Australian Environmental Grantmakers Network (AM)
- Peter Hunt, AMP Foundation (AM)
- Gene Sherman, Sherman Foundation (AM)
- Michael Traill, Social Ventures Australia (AM)
- Robert Trenberth, Director, Foundation for Young Australians (AM)
- Leigh Wallace, Lord Mayor's Charitable Foundation (OAM)

Congratulations also to Professor Patrick McGorry, Australian of the Year 2010, who was honoured with an AO.

A full list of this year's Honours is available on the Governor-General's website: www.gg.gov.au

New medical research prize

The National Health and Medical Research Council has announced a new medical research prize for left-of-field projects – The Marshall and Warren Project Grant Awards. The award is named for Professor Barry Marshall and Dr Robin Warren who shared the 2005 Nobel Prize in Physiology or Medicine for discovering the link between the bacterium *Helicobacter pylori* and ulcers and gastritis. The new prize will recognise potentially transformative research ideas and reward innovation.

Sir Gustav Nossal

This is an edited transcript of a speech **Sir Gustav Nossal**, Patron of Philanthropy Australia, gave at the launch of the Health and Medical Research Forum in Melbourne on 27 May 2010, reprinted here with his kind permission. Sir Gustav started by explaining how philanthropy contributes to the funding of medical research globally.



Let's begin with some macro-statistics and I'm speaking globally and in US dollars. Research and development is big business. Globally, R&D in all fields is a \$1.6 trillion business – that's \$1.6 million, million dollars, which is 2 per cent of global GDP.

Health and medical research constitutes about \$200 billion of the \$1.6 trillion, or 12 per cent of the total. In the United States medical research is of the order of \$90 billion annually, and \$30 billion of that comes from the government, so you'll see that the government only spends one dollar out of three in that great country.

Now in Australia, still using US dollars, the spend rate on health and medical research is around \$3 billion, which is about 1.5 per cent of the global total. Over 50 per cent of that comes from Commonwealth and State Governments, about 30 per cent comes from industry, about 12 per cent comes from philanthropy, and overseas grants make up the remaining 4 per cent.

Access Economics recently studied the economic impact of health and medical research spending, they came up with an up to six-to-one return on investment – and that's regardless of the humanitarian and health benefits.

'Well', you'll say '12 per cent of health and medical research funding coming from philanthropy isn't very much. Does it really make a difference?'

I want to tell you a story. Many years ago, in the late 1970s, the redoubtable Sir Clive Fitts – the fabled thoracic physician from the Royal Melbourne Hospital and a doyen of Australian medicine – asked me to join the Felton Bequest Committee. He was Chairman at that time, and a lot of the charity side

of the bequest was going to medical research. In time I was made Chairman, following Sir Clive, which put me in a difficult situation as a director of a medical research institute because of a potential conflict of interest, so I questioned whether this money should be going to medical research.

So we got some of the most senior, most thoughtful people in medical research around a table, and these men and women paraded example after example of where the philanthropic components of their budgets had made a real difference: equipment purchases, at that time quite difficult to get through government sources; flexibility, not having to be constrained by government politics or policies; risk taking, particularly risk-taking on younger researchers.

Prof Don Metcalf is a great example: years ago, as a young doctor, Don applied to what was then the Anti-Cancer Council of Victoria (now Cancer Council Victoria) for the Carden Fellowship, named after the relatives of our great soprano Joan Carden who had bequeathed some money to cancer research.

So this young blade, fresh out of residency training applied, saying "of course, as a junior, the salary you advertise is far too big for me", but the Anti-Cancer Council took a punt on him – that's what philanthropy can do. And 50 years later Don Metcalf is Australia's leading cancer researcher who's work has contributed to improve literally millions of cancer sufferers' lives. My conscience was stilled, although we did reduce the amount going to medical research, the grants persisted for some years.

Speaking of endowed chairs, I want to mention another one I've been marginally associated with, but which is really the brainchild of Bruce Bonyhady, Philanthropy Australia's remarkable chairman. Bruce had been talking with Associate Professor Dinah Reddiough (the soon-to-retire physician at the Royal Children's Hospital who looks after Cerebral Palsy and has a global reputation in that field), about creating a Chair of Developmental Pediatrics to research the causes of cerebral palsy and other severe developmental defects, looking into genetic abnormalities and treatments, and into prevention. Bruce has managed to secure about half of this endowed Chair from the Apex Foundation, and the other half is being rapidly assembled. This Chair should be a reality in the very near future – once again, private philanthropy at work.

Now a few words about the seamless continuum of health and medical research (see diagram). I want to remind everyone that the crucible is basic science, the molecular and cellular processes of normal functioning of cells and organs and how they go wrong. It's hard for audiences, particularly lay audiences, to grasp this but basic and fundamental science remains the essential core of medical research and must at all costs be protected. In immunology it's the basis of new vaccines, the basis of fighting auto-immune disease, the basis

Medical research continuum



for organ transplants sticking in the body rather than being rejected, and the basis of allergy and how to treat it. So we must continue to invest in basic science.

“...basic and fundamental science remains the essential core of medical research and must at all costs be protected.”

Then we move to more applied or developmental research that essentially asks ‘how do things go wrong in disease?’ Applied research uses test tube or animal models, sometimes quite crude, of disease processes. And all of that pre-clinical research then readies us for real translational research – how do you take the insights that come from basic research and applied developmental research into the clinic to find new diagnostic tools, new preventative therapies, new therapeutic modalities? Which of course means clinical research and clinical trials. And eventually this chain of research leads to the introduction of a new therapy.

Then our research goes on beyond new therapies into population-based studies, epidemiological research. The question of the association of disease with lifestyle is hugely important, not least in the fields of obesity, diabetes and cardiovascular health. And finally, we come to health services research, which asks what is best practice, how do we deliver the health services most cost-effectively to the Australian and global citizens?

Now it is frequently said that Australian medical research is bunched up on the left side of this spectrum, and to a certain degree that’s true – we are best known for our contributions to basic research. But I remind you that, of our six Nobel Prizes in medicine, three have actually come from people who have spanned the full spectrum, bench to bedside, so that’s worth remembering.

Now what are the gaps in Australia? We do lots of clinical trials, and the National Health and Medical Research Council’s (NH&MRC) Clinical Trials Unit is a very effective and helpful group. But, most of those clinical trials are done for big multinational pharmaceutical companies. It is quite difficult in Australia for either a university department or a small start-up biotech company to take a discovery all the way through to the clinical trials and thereby reap, eventually, the commercial and financial benefit for this country, rather than for a multinational based elsewhere.

That’s because our venture capital market is still thin, mezzanine financing is near-to non-existent in this country and this is a gap. Another gap, but one rapidly being filled, is what I’ll call

‘shared platform technologies’. It’s become evident that so much research is multidisciplinary and much of it depends on highly sophisticated and expensive equipment and technologies: genomics, magnetic resonance imaging, microscopy. One example I’m very proud of is the Australian synchrotron, based at Monash University – a \$206 million investment (largely by the Victorian Government) in a very highly sophisticated imaging technology.

“It is quite difficult in Australia for either a university department or a small start-up biotech company to take a discovery all the way through to the clinical trials and thereby reap, eventually, the commercial and financial benefit for this country...”

One of the best in the world in its size class, this synchrotron has been far more productive than we thought possible in the three years since its launch. The use of the synchrotron is boundless, across all fields of science, limited only by the imagination of the investigator.

Agricultural scientists will be doing one thing with it, medical scientists another, somebody working on new materials, someone else interested in quantum computing. We have nine beamlines operating on our synchrotron at present, but the machine has capacity for 36. Who is going to fund the remaining beam lines? We would like to suggest to government, state and federal, that they should come on stream with two extra beam lines per year at a cost of perhaps \$20 million per beam line. This is what I mean by expensive platform technologies and the difficulty of financing them.

Age and gender of our researchers is another major issue. Young Australians are too old by the time they become principal investigators – they have too long a period as post-docs on soft money, and that’s where philanthropy can step in and help. While more than 50 per cent of students in bio-medical research are female, the number who get to professorial rank is still only 10-12 per cent – a shocking waste of half of humanity’s talent. Doug Hilton, the new director of the Walter and Eliza Hall Institute of Medical Research has identified this as one of his top priorities: redressing the gender imbalance at the top of the tree in medical research.

So there is much to be done, but what an exciting time to be in medical research. I’d just love to be 25 again! ■



The importance of community wellbeing in promoting physical and mental health

By **Dr Kathleen Brasher** and **Professor John Wiseman** from The McCaughey Centre, VicHealth Centre for the Promotion of Mental Health and Community Wellbeing, School of Population Health, The University of Melbourne.

Internationally, and in Australia, there is growing interest in community wellbeing as a more holistic and accurate measure of societal progress than the dominant paradigm of economic growth. There is also an extensive body of evidence demonstrating the importance of community wellbeing as a crucial foundation for the promotion of physical and mental health.

As the Ottawa Charter for Health Promotion notes:

to reach a state of complete physical, mental and social wellbeing, an individual or group must be able to identify and to realise aspiration, to satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasising social and personal resources, as well as physical capacities. Therefore, health promotion is not just the responsibility of the health sector, but goes beyond healthy lifestyles to wellbeing.¹

From this point of view improvements in health outcomes depend as much on access to income, education, employment, good working conditions, high quality health services and a healthy and sustainable physical environment as they do on changes to individual health behaviours and lifestyles.

The VicHealth Mental Health Promotion Framework, applies this understanding to the field of mental health:

Mental health is not merely the absence of mental illness. Mental health is the embodiment of social, emotional and spiritual wellbeing. Mental health provides individuals with the vitality necessary for active living, to achieve goals and to interact with one another in ways that are respectful and just.²



Dr Kathleen Brasher



Professor John Wiseman

This article therefore aims to provide a brief introduction to emerging ideas about the definition and measurement of community wellbeing, along with an indicative illustration of the relationship between broader social and economic wellbeing trends and more immediate outcomes in the field of mental health.

Wellbeing – the capability to fulfil our full human potential

A sometimes sceptical response to the term 'wellbeing' is understandable, given the way in which the word has been co-opted by the marketers of day spas, aromatherapy and lifestyle magazines. However a more serious and significant debate about the nature of individual and community wellbeing is also emerging, informed by a long tradition of philosophical and scientific discourses concerned with understanding the relationship between 'the good life' and 'the good society'.

Modern definitions of the idea of wellbeing continue to draw much of their inspiration from the insights of Athenian philosophers such as Aristotle about the distinction between 'hedonic' and 'eudaemonic' wellbeing – wellbeing as immediate sensory pleasure versus wellbeing as the fulfilment of human potential. Aristotle also argued that as social animals our capacity to realise our individual potential is deeply effected by our social relationships. The wellbeing of communities is therefore an essential precondition for the wellbeing of individuals.

This 'eudaemonic' tradition is reflected in the work of the Nobel Laureate economist Amartya Sen who defines the purpose of economic development as expanding the capability – and therefore the 'freedom' – of individuals to fulfil their potential and to live lives of meaning and value.³

Many voices and traditions outside the Western canon also share the Aristotelian understanding of wellbeing extending beyond the sum of personal consumption and pleasure. For many Buddhists, 'happiness' does not refer simply to short term pleasure seeking but rather to the search for contentment and meaning which is most likely to be found through compassion and work with others. As a recent dialogue between Western psychology and Buddhism noted 'wellbeing ...is not simply stimulus driven pleasure emerging occasionally on the hedonic treadmill of life... Buddhism promotes an ideal state of wellbeing that results from... realising ones fullest potential in terms of holistic compassion and creativity.'⁴

Islamic views on wellbeing commonly begin by emphasising the importance of living both in accordance with the will of God and in following the moral and religious principles of the Koran. However there is also often a particularly strong focus on the idea of balance. Islamic scholar Izmar Muhir comments 'wellbeing is a state of integration and balance of all the different components of the human being: body, mind and

soul. Only when these components are balanced and harmonised is it possible to be transformed in a full human being able to realise one's own potentialities.⁵

Interestingly, the vocabulary of Indigenous Australian languages does not include a word which translates 'health and wellbeing' in any simple way.

The word 'punyu', from the language of the Ngaringman of the Northern Territory explains that concepts and functions of health and wellbeing must be considered from an interdisciplinary approach. Punyu encompasses person and country, and is associated with being strong, happy, knowledgeable, socially responsible (to take care), beautiful, clean and safe – both in the sense of being within the law and in the sense of being cared for.⁶

It is not surprising therefore that Indigenous wellbeing priorities extend beyond physical and material needs and desires, to include a broader range of wellbeing priorities including: spirituality, knowing about history and culture, education, knowing family history, being with family and extended family, being able to share with family and friends.

Subjective and objective wellbeing

The primary focus of subjective wellbeing research has been on the ways in which individuals evaluate their own lives. For psychologists, subjective wellbeing is part of a broader construct called 'quality of life'. Subjective wellbeing can be measured by asking people how satisfied they are with various aspects of their lives such as standard of living, personal health, individual achievements, personal relationships, personal safety, community-connectedness, future security and spirituality meaning.

Conversely, studies of objective wellbeing are more concerned with the empirically observable material conditions effecting the lives and opportunities of individuals and communities. These might for example include life expectancy, income, nutrition, employment, education, or democratic participation.

While there is something of a tradition of subjective and objective wellbeing champions ignoring and talking past each other a more fruitful dialogue is now emerging in which there is increasing recognition that a fully rounded picture of wellbeing requires a thoughtful mix of subjective and objective indicators and measures.

Community wellbeing

A third important aspect of 'wellbeing' involves shifting our gaze to the relationship between individual and community wellbeing. Again, there is much to learn from the experience and insights of Indigenous communities: Indigenous health is not just the physical wellbeing of an individual but the social, emotional and cultural wellbeing of the whole community in which each individual is able to achieve their full potential as a human being thereby bringing about the total wellbeing of the community.

"Like more traditional risks, the harmful effects of the degradation of ecosystems are being borne disproportionately by the poor."

The recent OECD edition of social indicator trends, 'Society at a Glance' makes a similar observation: 'people's happiness depends to a large extent on the circumstances of the broader community they are part of and their relationship to it.'¹⁷

The WHO Millennium EcoSystem Assessment Report also provides a compelling case for a far more informed understanding of the relationships between natural and built environments and the physical, mental and social wellbeing of individuals and communities with Director-General Lee Jong-Wook noting:

Nature's goods and services are the ultimate foundations of life and health. Health risks are no longer merely a result of localised exposures to traditional forms of pollution. They are also a result of broader pressures on ecosystems, from depletion and degradation of freshwater resources to the impacts of climate change. Like more traditional risks, the harmful effects of the degradation of ecosystems are being borne disproportionately by the poor.⁸

Informed by these various insights and principles, a working definition of community wellbeing could be framed in the following way:

Community wellbeing is the combination of social, economic, environmental, cultural and political

conditions identified by individuals and their communities as essential for them to flourish and fulfil their potential.

At a broader political and policy level, the concept of community wellbeing is also being increasingly employed to provide a more comprehensive framework for measuring and understanding the 'progress' of societies. As noted at the recent OECD World Forum on Measuring and Fostering the Progress of Societies:

Around the world... a consensus is growing about the need to develop a more comprehensive view of progress – one that takes account of social, environmental and economic concerns – rather than focussing mainly on economic indicators like Gross Domestic Product (GDP).⁹

Some great work has been done to develop several composite wellbeing or 'quality of life' indexes. The United Nations' Development Program Human Development Index, is based, for example, on a weighted composite of GDP per capita, life expectancy and years of education. The Gendered Development Index aims to capture the ways in which gender differences intersect with and influence wellbeing outcomes. The Genuine Progress Index brings together a range of measures which aim to take account of the costs as well as the benefits of economic development. The government of Bhutan has drawn on the Buddhist tradition to develop a 'Gross National Happiness Index' as a broader and more balanced measure of progress than Gross Domestic product.

An alternative approach to a single composite index has been to construct a suite of indicators providing a comprehensive picture of progress and wellbeing in a particular nation or region, e.g. The United Nations Millennium Development Goals and Indicators, European Union's Social Indicator Framework, and Canada Wellbeing Measurement Act.

Australian work on measuring and understanding community wellbeing trends has paralleled and at times led the global renewal of work in this area. The Australian Bureau of Statistics' publication 'Measuring Australia's Progress' has set an international benchmark for a national approach

to identifying and communicating data on wellbeing trends and outcomes.¹⁰

In Victoria the Community Indicators Victoria (CIV) project has led to the development of an integrated framework of community wellbeing indicators grouped according to five overall domains.

- Healthy, safe and inclusive communities.
- Dynamic, resilient economies.
- Sustainable built and natural environment.
- Culturally rich and vibrant communities.
- Democratic and engaged communities.

The CIV website provides a useful starting point for measuring and tracking community wellbeing trends and issues at local community level.

www.communityindicators.vic.gov.au

Community wellbeing and the promotion of mental health

Beyond the philosophical discussions, a key question for philanthropists to consider is: to what extent is the idea of community wellbeing a useful tool for understanding the relationship between broader social, economic and environmental trends and the improvement of specific physical and mental health outcomes? The following overview of recent evidence compiled by VicHealth and the World Health Organization on key drivers and determinants provides a useful starting point for exploring this relationship further.

1 The relationship between the prevention of violence and the promotion of mental health

- Intimate partner violence is the leading contributor to death, disability and illness in Victorian women aged 15-44 years, surpassing many well-known preventable risk factors such as high blood pressure, smoking and obesity.
- 57 per cent of Australian women report experiencing physical violence or sexual assault by a man over their lifetime.
- One in six young people between the ages of seven and 17 are bullied by their peers each week in Australian schools.

- People exposed to bullying are more likely to suffer depression and other psychosocial problems such as low self-esteem, poor self-concept, loneliness and anxiety.

2 The relationship between reducing discrimination and the promotion of mental health

- Discrimination adversely affects mental health by contributing negatively to psychological stress, anxiety, and major depression, as well as by limiting access to other resources required for good health such as employment and education.
- Recent Australian studies have highlighted both a high rate of exposure to racial discrimination among people from culturally diverse backgrounds and a large proportion of Australians holding racist attitudes.
- Suicide rates are significantly higher among Indigenous young people than for young people across the whole population.

3 The relationship between social inclusion and the promotion of mental health

- There is a strong positive correlation between social inequality and levels of emotional distress.
- People who are socially isolated or excluded have between two and five times the risk of dying prematurely from all causes compared to those who maintain strong ties with family, friends and community.
- Social support, social networks, community engagement and participation are key foundations for positive mental health.
- 16 per cent of Australian households cannot afford to participate in social activities such as family holidays, having a night out, or having family or friends over for a meal.

4 The relationship between economic security and the promotion of mental health

- People with low education levels, low status occupations and low incomes have relatively poorer mental health.
- Unemployed people and their families suffer a substantially increased risk of premature death, higher levels of depression, anxiety and distress

as well as lower self-esteem and confidence than employed people.

- While unemployment has a detrimental affect on wellbeing, so too does employment in poor quality jobs. People in jobs with several psychosocial stressors – job strain, job insecurity, marketability – report health that is no better than the unemployed. Other studies have reported that job stress – the combination of high job demand and low job control – predicts adverse health outcomes.¹¹

Conclusion

This article has endeavoured to provide a starting point for further discussions about the potential for community wellbeing to provide a useful conceptual framework for the promotion of physical and mental health, informed by an understanding of a reciprocal relationship between individual and community health and wellbeing.¹² ■

www.mccaughheycentre.unimelb.edu.au

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Jack Brockhoff Chair of Child Public Health: the outcome of a shared philosophy

By **Robin Marks**, The Jack Brockhoff Foundation, **Dr Lisa Gibbs** and **Professor Elizabeth Waters**
The Jack Brockhoff Child Health and Wellbeing Program, McCaughey Centre, University of Melbourne.



Robin Marks



Lisa Gibbs



Elizabeth Waters

In early June 2010, Directors of The Jack Brockhoff Foundation were delighted to attend a series of presentations by members of the Jack Brockhoff Child Health and Wellbeing Program on highlights of their community – connected projects. The research, with both its short and long term outcomes, was outstanding. What lay behind these presentations represents a collaboration between two groups with a shared philosophy – one a philanthropic trust and the other an academic team with a palpable passion for seeking out and overcoming the root causes of common handicaps to the development of healthy and well-adjusted young people.

The funder's story

In 1979 Sir Jack Brockhoff established The Jack Brockhoff Foundation with a donation of \$5.2 million, which was enlarged by a further bequest of \$5.8 million on his death in 1984. The Foundation has gone on to become one of the largest philanthropic trusts in Victoria, disbursing grants of over \$80 million since its inception.

Although Sir Jack did not have any children he had an interest in young and disadvantaged people, helping them in many ways throughout his lifetime. In establishing the Foundation, one of his major aims was to provide support for those working on programs to provide positive and enduring health and wellbeing for young people. "Give young people a good start in life" was his philosophy.

In 2008, 100 years after his birth, the Board of the Foundation resolved to offer a substantial and enduring grant as a memorial to Sir Jack. It was decided to support an academic community using the public health approach to attaining and maintaining child health and wellbeing.

Three groups from large Victorian academic institutions were invited to submit tenders. Three outstanding proposals were received. The decision was made to enter into a collaborative venture with the University of Melbourne. The work of the University's child health research team led by Professor

Elizabeth Waters so impressed the Jack Brockhoff Foundation that it dedicated a \$5 million award to support and strengthen research and knowledge exchange, leading to improvements in child health and wellbeing.

Professor Waters was inducted as the inaugural Jack Brockhoff Chair of Child Public Health on 23 March, 2009. The collaboration was launched on 22 October 2008 with a performance by children at St Matthew's Primary School, Fawkner North as part of the 'fun 'n' healthy in Moreland' child health promotion and obesity prevention study being conducted by Professor Waters and her team.

"...this was not going to be a virtual, anonymous funding arrangement regulated through extensive paperwork, but instead was going to be an opportunity for shared learning."

The recipient's perspective

Forming an ongoing relationship with a funding organisation that shares our commitment to child health and wellbeing was a dream come true for our McCaughey Centre-based research team. It became clear early on that this was not going to be a virtual, anonymous funding arrangement regulated through extensive paperwork, but instead was going to be an opportunity for shared learning. The Jack Brockhoff Child Health and Wellbeing Program aims to deliver tangible improvements in health and wellbeing for children. In partnership with rural and urban communities throughout Victoria, the Program is assessing and analysing child health and wellbeing; identifying key problems; such as obesity, poor dental health, accidents and morbidity; developing and implementing intervention strategies in cross community settings; and evaluating outcomes and effectiveness.

The Jack Brockhoff Foundation Board demonstrated their experience in the field of public health through an understanding that it is necessary to develop over time a suite of integrated research programs to understand the complex influences on child health and wellbeing. For example, the team's involvement in a range of school and community based child obesity prevention studies has culminated this year in the production of research findings from a wide range of communities across Victoria. The team is now in a period of in-depth analysis, comparison and discussion with academic colleagues and the State Government to immediately inform the direction of government policy and action.

Stable funding which is not allocated to specific activities provides the flexibility for the Jack Brockhoff Child Health and Wellbeing Program to be responsive to emerging community needs such as the 2009 Victorian bushfires. The fires caused much loss of life, property destruction, and community disturbance. It is important that an accurate understanding is achieved of the factors that contribute to optimal recovery from these natural disasters.

Professor Elizabeth Waters brought together a team of academic researchers, government bodies, disaster management agencies, and health and community organisations from affected communities to develop a five year research study that would build understanding of individual and community recovery needs and provide crucial information for shaping policy for disaster management in the years ahead. The team's expertise in child research will ensure that the voices of children and adolescents will be heard in this study and their perspective of recovery needs taken into consideration.

"A shared passion between the research team and a major funding organisation is a rare opportunity to capitalise on the expertise, resources and energy of both groups..."

The long term stability and infrastructure provided by the Brockhoff Foundation funding, which is being accessed through annual distributions each of several hundred thousand dollars (plus the net income earned through investment of the undistributed balance of the award), supports the development of the research programs through the different phases of research. This is necessary to achieve a strong level of evidence about what makes a difference; i.e. initial exploratory research, community intervention and evaluation, and then programs conducted at broader population level.

Ongoing core funding frees time normally spent in preparation of endless funding submissions and ensures stable employment for key members of the research team. This allows us to establish strong networks with community partners, policy makers and service providers to ensure that the research findings are shared and able to influence policy and practice. A shared passion between the research team and a major funding organisation is a rare opportunity to capitalise on the expertise, resources and energy of both groups and has been an extremely positive experience for the Jack Brockhoff Child Health and Wellbeing team. ■

Getting started in medical and scientific research funding

By Daniel Rechtman, Chairman, The CASS Foundation.

In 2001, when the CASS Foundation was established as a medium-size philanthropic organisation with the aim of funding education and medicine/science research, the Directors were told that the majority of funding for medical and scientific research came from government and industry, and that philanthropy contributed only a small amount.

Undeterred by this news, we determined to find a role for the CASS Foundation in the medicine/science research field and began by exploring if there were any gaps in government and industry funding that we might fill. We consulted widely amongst the medical and scientific research community and were delighted to find out how approachable and responsive to our enquiries even the most senior people were.

These conversations encouraged us to organise a two day workshop in 2002 attended by a number of senior scientists, including recent Nobel Laureate Professor Peter Doherty and the then Commonwealth Chief Scientist Dr Robin Batterham. We also invited the 2002 recipients of the Victorian Premier's Science Prize winners to gain the perspective of these early career researchers. We asked them to share their experiences of sourcing funds for research, and tell us what they thought the philanthropic sector might be able to contribute to their ongoing work. The researchers were frank in their comments and the CASS Directors realised that despite the predominance of government and industry as funders, there was a real opportunity for the Foundation to offer more flexible and venture-based funding for research.

From the workshop we learned that there were two significant areas where the kind of funding a Foundation like ours could provide might make a difference:

- 1 'Proof of concept' funding, particularly to younger researchers who did not yet have a track record in the field that would enable them to attract ARC or NH&MRC funding.
- 2 Travel Grants to early career researchers to assist them to attend and present papers at international conferences.

These two areas became, and still are, the Foundation's primary focus in the medicine and science areas.

'Proof of concept' funding exists at the threshold of discovery. It supports research into promising ideas, concepts and hypotheses that the organisation hopes to be able to validate as worthwhile and appropriate for further full-scale research and development.

Medical and scientific research is detailed and painstaking work. For every 'breakthrough cure' reported in the media, there are many projects that don't bear fruit, but which are

nevertheless important ground-breaking work for later researchers to build upon, or from which new applications and laboratory methodologies are derived.

We have found that built into 'proof of concept' funding is an assumption of risk – the acceptance of the possibility that a project may not succeed in its original aim, but that it will nevertheless contribute to the sum of scientific knowledge.

For philanthropists there are advantages in 'proof of concept' stage funding in terms of being able to encourage bright young researchers; and perhaps only the philanthropic sector is likely to fund 'untested' projects in the foreseeable future. This type of funding also ensures flexibility in grantmaking, as there are literally hundreds of prospective research areas and projects from which to choose. The opportunity for leveraged funding and co-operation with other funders is also high, as is the satisfaction of following good people over the long term and tracking their careers.

Evaluation

My colleagues and I are often asked about how 'proof of concept' research grants can be evaluated. The CASS Foundation requires successful applicants to enter into formal Grant Agreements, in which the grantees identify stages in their proposed research pathway and determine likely or appropriate outcomes at each point. The outcomes can then be measured progressively against this schedule. We believe (and we've had feedback from researchers to this effect) that this requirement assists scientists to clarify their process and methodology and to plan the probable progression of their enquiry; these are very useful work management skills for career researchers.

In the decade since 2000, CASS has funded 119 separate science and medicine projects across a vast array of topics, ranging from the purest of abstract basic research to very practical, hands-on applied research seeking to make changes to clinical practice and treatment. The possible areas for consideration have been limited only by the imagination of the researchers and the interests of the Foundation's Directors and staff.

What encourages the CASS Directors to continue funding in this area is that we have been able to see projects develop from a promising idea to a proven concept, leading to longer-term funding and (sometimes) finally to improvements in treatment or clinical practice.

In preparing this article, I have gone back over our grants and am surprised at the range of projects funded. Successful examples of research include:

- cord blood cell therapy for cystic fibrosis;
- pressure cast techniques to assist low-cost prosthetic limb production (for use in under-developed countries);
- investigations of new strains of Australian golden staph;
- development of a microbot 3D neural navigation device; and
- use of rodent hair follicle stem cells for cardiac muscle cell engineering.

The following extract from a recent project report is indicative of the positive results that can come from early research project funding:

"In essence, the ultimate goal of this project was realised in June 2010 and, gratifyingly, may change the practice of cord blood banking and selection of cord blood units for transplantation, leading to improved patient survival and quality of life. This study would not have been possible without the preliminary studies that were initiated and completed with funding from the CASS Foundation."

Travel Grants to early career researchers

Our second area of medical/science funding is in offering two rounds of Travel Grants each year to assist early career researchers to attend and present papers at international conferences, and to visit overseas research facilities and meet leaders in their field of interest. So far, CASS has provided 239 Travel Grants to researchers from all over Australia.

The CASS Travel Grants assist recent PhD graduates and younger researchers to place their feet firmly on the career ladder and establish professional networks and research collaborations internationally. An endorsement from a recently returned grantee is illustrative:

"As an early career researcher, the opportunities that have arisen from my attendance at the 2010 American Society of Andrology Meeting exceeded all expectations and I sincerely thank the CASS Foundation for enabling me to attend. I left (the meeting) feeling inspired, with a strengthened resolve to achieve my career objective of becoming an exceptional leader generating research that will significantly advance human reproductive health."

The CASS Board proposes to continue both 'proof of concept' research grants and travel funding as we are convinced that they fill a gap in the current funding mix, and are a satisfying and worthwhile area of grantmaking. We know that the research community is anxious to see these areas of funding expanded.

From time to time we have the privilege of watching our 'seed' funding blossom into tangible medical and scientific outcomes. What we have learned since we began is that it does not necessarily take a large amount of funding to create a worthwhile difference and one does not always have to wait a long time to receive evidence of productive results.

The challenge for philanthropic organisations is to find out what they wish to fund, where the real needs are and how they can best be met. There is no shortage of important medical and scientific research waiting to be funded and philanthropists new to this type of funding will be able to find many, worthy and interesting start-up research projects to support.

It is my hope that the recently implemented Health & Medical Research Forum (a joint initiative by Philanthropy Australia and Research Australia, launched by Sir Gustav Nossal in late May 2010) will encourage others to recognise the potential for practical giving in this interesting field. ■

www.cassfoundation.org.au



Tackling the chronic conditions affecting society's most vulnerable

By **Jane Austin**, Senior Director, Communications and Philanthropy at The George Institute for International Health.

When we think of epidemics, we typically think of tropical flu or other infectious diseases. But a decade of research at The George Institute for International Health tells us that in Australia we are confronting an epidemic of chronic disease, including diabetes, kidney disease and stroke – and that these take the biggest toll on human life. Chronic disease will claim 400 million lives globally by 2020, with 3.5 million Australians already affected by cardiovascular disease alone. And not surprisingly it is our most vulnerable who are over represented in these statistics, with Indigenous Australians 2.6 times more likely to die from heart, stroke and vascular disease.

While many people have heard about 'closing the gap', few realise that most of the gap is attributable to chronic conditions that are, in many cases, preventable. By focusing research efforts on these chronic conditions in a pragmatic way, substantial progress can be made in a relatively short timeframe. This requires health research to produce findings that translate into action at the coal face of communities, and into the policies that aim to make healthcare more accessible and affordable for all.

Focusing on research with practical applications may be a challenge for a research community that has historically focused on academic publication as a key outcome. While citations remain a benchmark of scientific credibility, it isn't enough to convince philanthropists that projects are worth supporting – and rightly so. The science may be brilliant but what difference will it make to people's lives? How will it persuade governments to improve healthcare delivery or increase the quality and safety of treatments?

In addressing the Indigenous chronic disease gap, the Kanyini program, our collaboration with the Baker IDI Heart and Diabetes Institute, works with Aboriginal Medical Services to develop innovative models of care.



Indigenous communities and The George Institute are partnering for better health and social outcomes.

A philanthropic donation (from a private trust) allowed us to extend the reach of this work into a remote Indigenous community, where scarce specialists could be provided through a new Outback Vascular Health Service. Further funding will allow replication of this highly scalable model around Australia.

While traditional medical research funding sources often lack the bravery to back the untried, philanthropy can seed the well-thought-out projects that will go on to produce step changes in their field, and encourage other funding sources to then 'back a winner'. We encourage this 'Innovation Seed Funding' approach, which is ideally leveraged to attract significant multi-source funding to new programs or to extend and upscale existing, proven programs.

In another example, The George Institute and the University of Sydney were asked to partner with the Indigenous Fitzroy Crossing community to address the devastating effects of fetal alcohol spectrum disorders on their children. Here, more than health is at stake – fetal alcohol disorders rob children of their memory, undermining the passing on of the Dreamtime stories that are the lifeblood of Indigenous culture. In order to fully understand complex cultural issues and how to approach them, we had to undertake a significant and not inexpensive community consultation. Philanthropic support from Bellberry Limited, a not for profit organisation that manages

human research ethics committees, helped provide the crucial and tangible evidence to government, about the level of buy-in from the community. (An anonymous donor also came on board to fund Phase One of the project.)

With its clear, unapologetic focus on impact, philanthropy ensures researchers aren't operating in a vacuum, but are tuned in to what society really cares about. This should in turn, feed into the heart of an institute's strategic development and force questions about the true, societal value of work being undertaken.

As a hub of leading and future 'people scientists', we are never short of innovative ideas – whether it be understanding what makes young drivers take risks, looking at the impact of YouTube and social networks on self harm, or developing new tools for GPs and health workers to better assess and manage cardiovascular risk. Our aim is to ensure this work has direct relevance to health and social priorities and is harnessed to enact the changes that will help people live better, healthier and longer lives. ■

www.thegeorgeinstitute.org

The George Institute for International Health delivers research, programs and innovations to better prevent and manage chronic conditions and injuries.

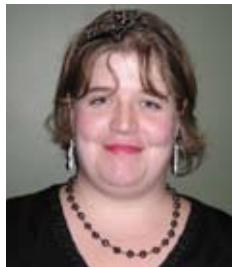


THE GEORGE INSTITUTE
for International Health



The Atlantic Philanthropies

By Mary Borsellino, Assistant Editor Australian Philanthropy.



It may not be a household name, but those in the know will recognise The Atlantic Philanthropies as Australia's largest philanthropic donor to medical research.

To date donations from The Atlantic Philanthropies (AP) to medical research in Australia exceed an astonishing A\$270 million. The impact of this generosity is compounded by The Atlantic Philanthropies' model of using matching or partnering grants from governments and universities.

Almost every single grant in Australia "was just one-third of the amount of money needed... One-third from us, one-third from the institution, and one-third from government." He leveraged more than half a billion Australian dollars on donations from Atlantic Philanthropies (*The Billionaire Who Wasn't*, p. 260).

To date, with Queensland and the Commonwealth governments matching the AP grants with \$177 million and \$325 million respectively, these partnerships have led to plans for building or expanding 19 university or medical research institutions throughout Australia to date.

For example: The Atlantic Philanthropies has given \$57 million to the Queensland Institute of Medical Research over the last 10 years, which allowed the Clive Berghofer Cancer Research Centre to be constructed, and is now funding a new state-of-the-art research facility to be completed in 2012. The Queensland University of Technology was given \$25 million, and \$50 million was given to the Princess Alexandra Hospital and the Translational Research Institute. The Atlantic Philanthropies has also helped establish the region's first stroke unit at the Royal Brisbane and Women's Hospital, whose outreach program

provides state-of-the-art treatment for inpatients and outpatients. The impact of this funding is felt far and wide. Professor Peter Andrews, Queensland Chief Scientist, believes that The Atlantic Philanthropies has enabled "a whole raft of new connections – connections between disciplines; secondly, connections between research and end users like industry and others; and thirdly, the international connections". Professor Andrews has also explained that "the biotech industry here was virtually nonexistent 10 years ago: zero drugs out of Queensland biotech were in clinical trial; now there are 23. There are six or seven times as many workers, six or seven times as much revenue."

The flow-on effect on philanthropy has been in evidence too. In 2008 Clive Palmer gave a \$100 million grant for medical research in Western Australia – at the time Australia's biggest corporate donation. In 2005, Greg Poche handed over \$32.5 million for a melanoma unit at a Sydney hospital.

The Atlantic Philanthropies was established in 1984, when Chuck Feeney decided to embrace the philosophy of 'giving while living' and gave virtually all of his fortune to his new foundation. At first operating anonymously, The Atlantic Philanthropies has made worldwide grants totaling more than \$5 billion (as of December 2009).

The anonymous beginnings of The Atlantic Philanthropies have set the tone for its subsequent giving practices. Chuck Feeney declines all offers of public recognition such as naming rights and commemorative plaques at the institutions which The Atlantic Philanthropies supports. The organisation itself is registered in Bermuda in order to avoid the disclosure laws in place in the United States.

Acting with a global view, The Atlantic Philanthropies supports facilitating and accelerating the transfer of knowledge and research among medical researchers and university leaders in Australia, the Republic of Ireland, the

United States and Vietnam, as Chuck Feeney believes that together, world-class institutions are more likely to develop medical breakthroughs greater than any single institution would achieve alone.

"To date donations from The Atlantic Philanthropies (AP) to medical research in Australia exceed an astonishing A\$270 million. The impact of this generosity is compounded by The Atlantic Philanthropies' model of using matching or partnering grants from governments and universities."

Feeney leveraged cooperation as well as money. His attitude, he said, was "we can help you, but you have to help someone else." He incorporated Australia's universities into his growing world network... American, Irish, Australian and later South African and Vietnamese university heads, academics and scientists found themselves urged on by Feeney and The Atlantic Philanthropies to cooperate and help each other (*The Billionaire Who Wasn't*, p. 260).

Chuck Feeney has instructed The Atlantic Philanthropies board to pay out the Foundation's corpus by 2016. ■

www.atlanticphilanthropies.org

You can read more about Chuck Feeney and The Atlantic Philanthropies at their website and in the biography 'The billionaire who wasn't: How Chuck Feeney secretly made and gave away a fortune' by Conor O'Cleary (PublicAffairs, New York, 2007). It is available for Members to borrow in the Philanthropy Australia library.

Closing the gap – the Margaret Ross Chair of Indigenous Health

The funder's perspective

By **Anne Grindrod**, Chairman, John T Reid Charitable Trusts.

The ultimate goal of philanthropic funding for health is improved community wellbeing. Over 50 years of philanthropy, the John T Reid Charitable Trusts have made major contributions to improving health outcomes in the Australian community.

Significant grants to institutes and universities have supported academic research through seeding the establishment of specialist laboratories, funding for fellowships and scholarships and the purchase of diagnostic equipment. The John T Reid Charitable Trusts recognise the importance of collaborative research, from the advancement of clinical trials to expedite pure research to improved patient care and the need for community support and education.

Research and development take time and financial commitment. Funding opportunities to venture advances in medical science involve risks and rewards that require careful consideration. We have found that working to support the vision of Australia's internationally recognised researchers and clinicians has produced very satisfying outcomes. Building relationships for long term commitments has led to progress in some of the most protracted health issues. Our experiences show that funding preventative health initiatives, equitable access for health information, support for remote health programs and targeting disease and disadvantage helps to promote better health in the wider community.

Responding to community concerns about preventative health and wellbeing for Indigenous Australians, the Trustees of the



Professor Paul Zimmet, Director Emeritus and Director International Research; Professor Garry Jennings, Director Baker IDI; Mrs Margaret S Ross AM; Mrs Belinda Lawson and Dr Alex Brown, Margaret Ross Chair of Indigenous Health and Executive Director Baker IDI Central Australia at the opening of the W&E Rubuntja Research and Medical Education Building.

John T Reid Charitable Trusts supported the establishment of the Chair of Indigenous Health as part of Baker IDI's involvement in Indigenous health in Central Australia. This initiative culminates years of commitment to research programs at Baker IDI and many funding commitments in remote health, traditional healing and preventative and community Indigenous health. We are encouraged by the plans for collaboration at the new research facility in Alice Springs. The Trustees proudly agreed to name the Chair of Indigenous Health in honour of Margaret Ross AM, who retired last year after 25 years as Chairman of the John T Reid Charitable Trusts. ■

The research institute's perspective

By **Carolyn Williams**, General Manager Development and Fundraising, Baker IDI Heart & Diabetes Institute.

The health disadvantage of Indigenous Australians represents one of Australia's most enduring social and health divides.

Cardiovascular disease, diabetes and chronic renal disease are the primary contributors to the 17 year gap in life expectancy between Indigenous Australians and non-Indigenous Australians.

In the context of these alarming figures, and as part of Baker IDI's mission to reduce death and disability from cardiovascular disease, the Centre for Indigenous Vascular and Diabetes Research was established in 2007. Based in Alice Springs,

the Centre was established to conduct community-based scientific and clinical research to improve the health of Indigenous Australians.

Indigenous doctor leads the way

Led by Indigenous physician Dr Alex Brown, the work of Baker IDI in Central Australia aims to harness the Institute's resources to help address the profound disadvantage experienced by Indigenous Australians, and to a build long term, strategic platform for health and medical research to assist these communities.

By anyone's standards, this is an enormous challenge that requires significant resources, commitment and collaboration. But thanks to the incredible foresight and generosity of the John T Reid Charitable Trusts, a Chair of Indigenous Health was established in 2010 to spearhead Baker IDI's advances to 'Close the Gap' in Indigenous health in Central Australia. With a decade of experience working in Aboriginal Health and education, policy, communicable disease control, service delivery, epidemiology and research, Dr Brown has now been appointed to The Margaret Ross Chair of Indigenous Health.

Focus on education, advocacy and strategic research

Under his leadership, and with the support of a growing number of investigators focussed on Indigenous health research in both Alice Springs and Melbourne, a great deal has already been achieved. This includes the construction of a new research facility in Alice Springs called the W&E Rubuntja Research and Medical Education Building, which opened in March 2010. Located within the grounds of the Alice Springs Hospital, the building is the new home for Baker IDI Heart & Diabetes Institute in Central Australia and Flinders University's Northern Territory Rural Clinical School.

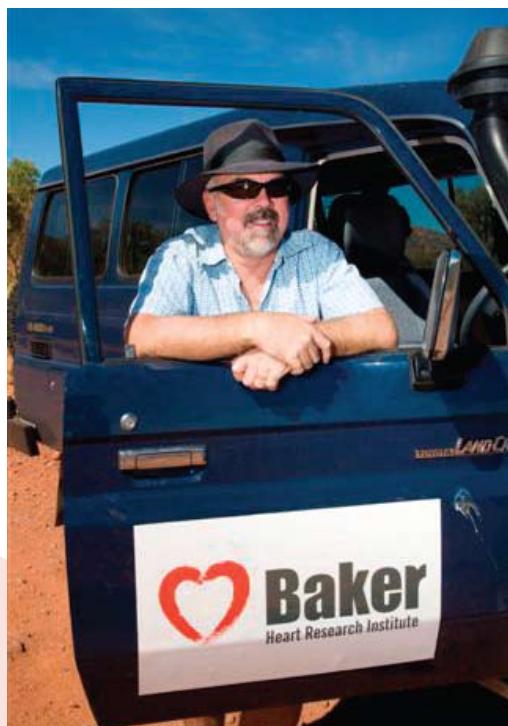
"The collaborative partnerships with local healthcare providers, such as the Alice Springs Hospital, also serves to create the infrastructure needed to put in place effective long term health strategies."

The facility provides a coordinated base for Baker IDI to continue to develop effective chronic disease prevention and management programs, as well as build capacity amongst local healthcare workers. The collaborative partnerships with local healthcare providers, such as the Alice Springs Hospital, also serves to create the infrastructure needed to put in place effective long term health strategies.

The first of a series of educational symposia for healthcare workers in Central Australia was held in 2009, with plans already underway to hold more of these events in 2010 and 2011. More than 100 healthcare workers attended the first symposium, with the event confirming the value of sharing resources and promoting education and advocacy in Central Australia.

The Margaret Ross Chair of Indigenous Health also supports long term research programs, aimed at establishing baseline data, overcoming barriers and developing preventative strategies, as well as enhancing treatment and care, specifically for Indigenous communities with their own unique healthcare needs. These include research on:

- the 'Heart of the Heart' program which assesses the cardiovascular health risk of hundreds of Indigenous Australians;
- identifying and overcoming barriers to chronic disease experienced by Aboriginal people;
- examining stress and depression in Aboriginal men in Central Australia; and
- auditing the identification, management and treatment of elevated vascular risk.



Mobile Cardiovascular Assessment unit.

Collaboration based on respectful relationships

Since establishing a presence in Alice Springs in 2007, the approach of Baker IDI Heart & Diabetes Institute has been based around a close engagement with Indigenous communities affected by chronic disease, and the many community organisations, universities, medical research institutes and government agencies already involved in research and service provision in the region. The groundswell of work that Baker IDI is undertaking is only possible with strong relationships with these agencies and communities, in order to build a critical mass to improve the outcomes for Indigenous communities.

The new research facility also provides another focal point for Baker IDI medical research activities in collaboration with the Hospital and local Indigenous communities. Mrs Margaret and Dr Ian Ross, and Mrs Belinda Lawson, Trustee of the John T Reid Charitable Trusts attended the opening of this facility in March 2010, taking the opportunity to meet the research team and hear first-hand about their collaborative-based approach which is driving real change in Central Australia.

It is this integrated, coordinated approach that represents a very real, dynamic and exciting new chapter in the efforts to drive much-needed change in these communities which are hardest hit by diabetes and heart disease and it is most encouraging for all involved to have the John T Reid Charitable Trusts significantly supporting these efforts. ■

www.bakeridi.edu.au

Learning from experience: the Ramaciotti Foundations

By **Claire Crethar**, Marketing Coordinator Philanthropy, Perpetual.

The Ramaciotti Foundations are collectively one of the largest private contributors to biomedical research in Australia, having granted more than \$47 million since 1970. Andrew Thomas, Perpetual's General Manager of Philanthropy, reflects on the key learnings as trustee of the Foundations as they approach their 40th anniversary.

Vera Ramaciotti established the Ramaciotti Foundations in 1970 to give substantial support to biomedical research – an interest shared by Vera and her brother Clive. She appointed Perpetual as trustee to manage the Foundations which began with \$6.7 million. Through careful investment, they have grown to be worth more than \$47 million and have granted more than \$47.5 million to biomedical research. This has been primarily through the annual Ramaciotti Awards which make grants to individuals and teams undertaking research in areas such as molecular biology, genetics and immunology.

Seek expertise when you need it

Philanthropy is our expertise, not medical research, so in 1971, we appointed a Scientific Advisory Committee (SAC) to advise the Ramaciotti Foundations. Seeking external advice has been a key element in the success of the Ramaciotti Awards to ensure grants are made to worthy and legitimate projects.

SAC members are selected based on a number of factors such as skills and experience in the medical field as well as distribution throughout the country, across a variety of institutions and medical specialties. They provide the Foundations with advice in relation to income distribution, policy and procedure for sourcing applicants, award guidelines and eligibility. While we provide the framework for the SAC, their expertise is invaluable to the decision making process and complements our experience in trust management.

A disciplined grantmaking process is essential

The Ramaciotti Foundations' grantmaking process centres on outcomes, enabling the Foundations to provide grants for projects and equipment that can achieve the greatest impact. Rather than focusing solely on the perceived worth of the project seeking funding, the Foundations look at the grantseeker's objectives, how they will achieve them and how they will measure the results. This process not only encourages quality grantseekers with viable projects and effective leadership, but also promotes best practice in grantmaking.

Evolve to stay relevant

While it's essential that we carry out Vera's wishes as she intended, it is also important that the Awards evolve to ensure grants remain relevant to the biomedical research community's needs. For example, in the 1970s the SAC introduced a one-off travel grant to encourage research cooperation between Great Britain and Australia. Due to its popularity and relevance, it stayed in place for 10 years.

In the 1990s the Ramaciotti Medal was introduced to acknowledge previous grant recipients who have made an outstanding contribution to their field, and in 2001 the \$1 million Biomedical Research Award for institutions was introduced to fund major projects and infrastructure.

Being adaptable to the needs of scientific community has meant greater achievements for medical research over time.

Share knowledge

We can't underestimate the great impact the Ramaciotti Foundations have had through the sharing of knowledge, on both the biomedical science community and our work at Perpetual as a provider of philanthropic services.

Firstly, we encourage grant recipients to share their research with other institutions to promote and advance biomedical



Vera and Clive Ramaciotti.

research. In many cases grant recipients have been chosen partly due to the project's potential to benefit the broader biomedical community. One example of this is the \$1 million grant that was made in 2009 to establish a centre for therapeutic drug research (Centre for Kinomics). Two laboratories will be built to provide resources for 23 participating NSW research teams. The result of this grant is far-reaching and allows for knowledge to easily be disseminated across the biomedical science community. A formal awards night has also enabled scientists to share their research with each other and potential donors who attend the event.

Secondly, managing the Ramaciotti Foundations and Awards over the last 40 years has taught us many things that can be applied to other charitable trusts we manage, and when advising our philanthropic clients. For example, working with the Ramaciotti Foundations has given us insight into what works best for sustainable philanthropy and provided us with a network of grantseekers who can be matched to the needs of our other philanthropic clients.

This November the Ramaciotti Foundations celebrate 40 years of supporting achievements in biomedical research. ■

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RAMACIOTTI 40
YEARS
SUPPORTING BIOMEDICAL RESEARCH

A ripple effect of benefits

By **Avalee Weir**, Communications Manager, The Ian Potter Foundation.

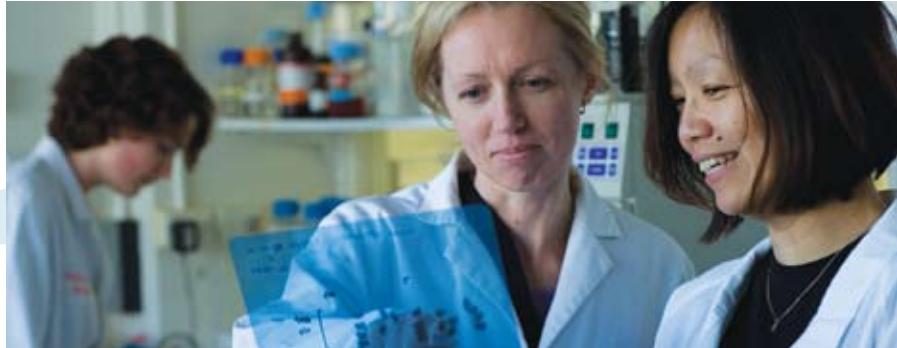
Medical Research has been a central part of The Ian Potter Foundation's giving since Sir Ian Potter identified the sector as one of great interest to him, and an area he deemed of major importance and benefit to the whole community. Some of the Foundation's first grants were directed to supporting significant medical research institutions and the talented people behind them. The fundamental principles of the approach first taken by Sir Ian and the expert advisors on the Foundation's original Board are still relevant, and remain at the core of the Foundation's approach to Medical Research grants.

"The science has changed a great deal since then," says Dr Tom Hurley, Governor of The Ian Potter Foundation, "But the decisions about where the money should be invested still come back to the same key requirement: that the program is of the highest standard – and that criterion extends to the people, the institution and the idea."

This approach has ensured a strong track record for The Ian Potter Foundation in medical research philanthropy, and given it the flexibility to seek out and support key areas of need. In every case, the Foundation assesses applications against a set of funding principles, which include:

- outstanding leadership;
- a focus on prevention;
- the potential for replication;
- the opportunity for partnerships; and
- the sustainability of the project.

The Foundation's grant to The University of Melbourne's Indigenous Eye Health Program is a good example of this. After seeing a report about the blight of the preventable, treatable eye disease trachoma in Indigenous communities, Janet Hirst, CEO of The Ian Potter Foundation, approached Professor Hugh Taylor to discuss how we could help. A proposal to the Foundation's Board led to \$1 million being committed. Professor Taylor went on to secure major government support which will go a long way to securing eye health in these communities.



Medical Researchers Peta Burns and Siew Yeen Chai examining an X-ray. The scientists are working in the Howard Florey Institute's Neuropeptides Laboratory (now part of the newly-formed Florey Neuroscience Institutes) which was established with a grant of \$1.2 million over five years (2002-2007) from The Ian Potter Foundation.

Central to the Foundation's work funding medical research is the expertise and knowledge of the Board of Governors, such as Dr Hurley AO, OBE and Professor Graeme Ryan AC, who make assessments of the medical research grant applications and make the recommendations to the Board. The majority of the Foundation's grants fund key equipment purchases and capital works to provide the infrastructure needed to allow the researchers to get the results.

The Foundation's program of travel grants is also highly successful, providing funding for talented early career researchers to travel overseas to present their findings, helping them to build networks, knowledge and credibility.

Our grant to The St Vincent's Institute of Medical Research's Blood and Bone Cancer Centre is a great example of the ripple effect of supporting researchers with potential. The funding helped pay for vital equipment which meant that leading young researchers Dr Louise Purton and Dr Carl Walkley could continue their ground-breaking research, and this helped the Institute attract additional ongoing funding.

Another very rewarding aspect is supporting promising experimental ideas and to assist them to evolve to a stage at which they can attract ongoing funding and support from the government and the large grantmaking bodies such as the NH&MRC. The Ian Potter Foundation was one of the initial supporters of the Bionic Ear and more

recently, provided a grant of \$500,000 to the Bionic Ear Institute's Bionic Eye project in which Australian researchers are trialling an avant-garde concept that has produced exciting early stage results. This project has now attracted major government support as well.

There are many examples of philanthropic funding assisting organisations to build the momentum and credibility required to leverage additional funding from other philanthropic donors and from government. The project that played a role in the establishment of The Ian Potter Foundation and paved the way for the Foundation's continued support for Medical Research was the Howard Florey Institute of Experimental Physiology and Medicine, which was established in 1963 after seed funding provided by Sir Ian and the Myer brothers, Ken and Baillieu. Now part of the Florey Neuroscience Institutes, 'the Florey' is The Ian Potter Foundation's single largest recipient of funding (over \$20 million) and considered one of the Foundation's most successful grant recipients, having grown to become one of the world's leading institutes in neuroscience.

This sector remains a vital part of The Ian Potter Foundation's work with \$37 million in grants committed to date. ■

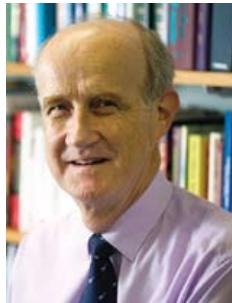
<http://www.ianpotter.org.au/>





The health risks of climate change: strengthening our resolve to act

By **Tony J McMichael**, Professor of Population Health, and NHMRC Australia Fellow
National Centre for Epidemiology and Population Health, The Australian National University
Canberra, Honorary Professor in Climate Change and Human Health, University of Copenhagen.



Most research (and research funding) in the climate change arena has focused on learning about the dynamics of the climate system and how to model valid projections of future human-induced climate change. However, we still know little about the full range of consequences of climate change; and how best to minimise those consequences while the international community struggles to mitigate climate change.

Following the disappointment of Copenhagen, in December 2009, public discourse about climate change has receded. Indeed, the recent severe shocks to the global financial system have eclipsed more fundamental long-range concerns about living sustainably. Yet there is urgent need to understand the stakes we are really playing for – particularly because the world community is, still, continuing to escalate global warming.

This unprecedented disruption of Earth's life-supporting systems portends major threats to the wellbeing, health and survival of human populations. Yet neither this fact, nor its profound significance, is well understood. However, the tide is beginning to turn. In May 2009, the eminent international journal *The Lancet* announced on its front cover that "Climate change is the biggest global health threat of the 21st century". That same month, the annual Commonwealth Health Ministers Conference, in Geneva – attended by 43 countries and chaired in 2009 by the Australian Government – also focused primarily on the topic of climate change and health.

We worry, meanwhile, about climate change impacts on economic structures and productivity, on jobs in some sectors, property values, the safety of physical infrastructure, and threats to iconic species and natural environmental assets. But the threats run much deeper. Climate change will not only bring temperature extremes, more weather disasters, and heightened air pollution levels. It will impair food yields in many regions, increase freshwater insecurity, alter the geography and seasonality of many infectious diseases, destabilise communities, enforce out-migration (e.g. rising seas, declining farm incomes) and its many adverse health consequences, and engender anxieties and mental health problems in many groups.

Climate change thus represents a threat to the constancy and content of the very life-support systems upon which humans and all other species depend. Species and

ecosystems everywhere have evolved to survive and thrive within the relatively narrow climatic 'window' that has prevailed over (at least) the past 10-15,000 years. We may think that our health depends mainly on supermarket choices, access to doctors and our gene set, but the fundamentals of health for us, and for all species, reside in the natural environment – and all depend on relative climatic constancy.

"The unusual long term future dimension of climate change and its resultant risks pose a supreme test for humans, a test of our capacity to take radical actions on behalf of The Future. That is a big deal."

Research that assists public understanding of these risks to physical and mental health, in human populations everywhere, will help focus our minds on the crucial need to develop ways of living sustainably within Earth's biocapacity. So, what are the main risks to health in Australia posed by climate change – and what are the particular research needs?

Part of the answer to that second question is that an increase in person-power is needed for this type of research. Much of the science is not easy. Causal relationships are often indirect – e.g. the mental health consequences of reduced farm yields and incomes that are occurring because of an emerging drying trend in parts of southern and eastern Australia. Much of the research must draw on multiple disciplines and professional skills, something that many highly-trained single-issue researchers are not willing or able to do. And, frustratingly, detecting the human health impacts of climate change is bedevilled by the 'noisy' background that typifies the culturally-embellished and behaviourally diverse human species. If sea-ice melts more rapidly, then it must be because the temperature has risen. If malaria emerges in the highlands of Papua-New Guinea, there are half a dozen candidate explanations (including recent warming), and they may all coexist and contribute.

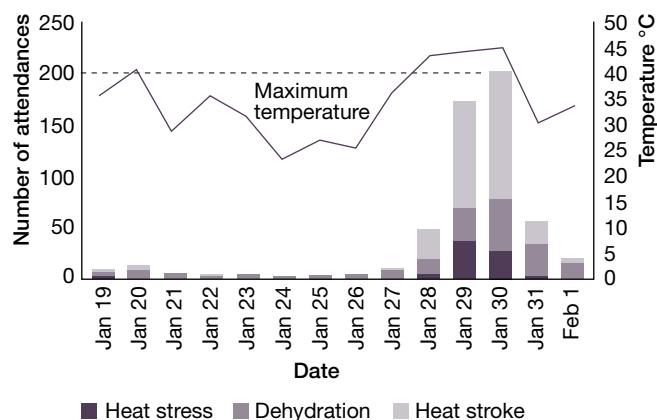
Fortunately, despite these difficulties, a small but growing number of health researchers in Australia is now engaging with climate change. There is, too, an increase in the number of recent graduates undertaking higher-level degrees in this topic area. Funds invested in this area will pay important and enduring social dividends.

In Australia we are predictably concerned about the likely rise in the toll on health, safety and survival caused by heatwaves and bushfires. Recent years have brought new extremes of both those exposures, and almost certainly that severity has been amplified by the underlying climate change in Australia (see diagram). Even so, we have a limited understanding of which population sub-groups are most vulnerable, and what combinations and characteristics of 'heat' episodes (duration, seasonal timing, coexistent air pollution, etc.) pose the greatest risks. Hospitalisation and mortality records are easier to assemble and analyse for urban than for rural and remote populations. What differences are there between the richer and poorer segments of the community? How do housing design and the layout of human settlements affect the health risks from heat extremes and fires?

Victoria 2009

- 27-31 January maximum temperatures.
- 12-15°C above normal.
- Temperature >43°C for three days, 28-30 January.
- 126 out-of-hospital deaths (vs 44 expected deaths) i.e. ~3-fold increase.
- 60 per cent increase, January 29-30, in ambulance call-outs.

Ambulance attendances for heat-related illnesses in Metropolitan Melbourne: 19 January-1 February 2009



Modified from: 'January 2009 Heatwave in Victoria: an Assessment of Health Impacts.' State of Victoria 2009.

Many infectious diseases are sensitive to climatic conditions. Diarrhoeal food-poisoning tends to occur most in summer. Mosquito activity is affected by temperature, humidity and rainfall. Climate change will alter the pattern of occurrence of many infectious diseases directly and via changes in surface water, vegetation, and (for some diseases) in populations of non-human 'reservoir' host-animals. We need much better understanding of these climate-disease relationships in Australia.

Those more readily recognised risks to human health have recently begun to attract research interest and funding. Meanwhile, however, there are other important aspects of the topic for which research and preventive policy development is seriously underfunded. For example, we need to learn about the following:

1 The stresses and anxieties that **children** experience about the future world they are likely to live in, and their struggle to understand why this is happening, pose risks to their emotional and social development. In financially stressed rural households, parent-child relationships and physical developmental opportunities may be impaired.

2 **Indigenous communities**, especially in remote settings, face many risks to wellbeing and health from direct environmental stressors (e.g. heat extremes, water shortages) and from the erosion of ways of living (e.g. losses of wild foods, impacts on livelihoods). Can 'caring for country' projects on traditional Indigenous lands yield 'bonus' benefits for social and emotional wellbeing while achieving adaptation to climate change?

3 **Rural communities** are bearing much of the brunt of the early phase of climate change in south-eastern Australia. The Murray-Darling Basin region is at particular risk: beyond the historical mismanagement of our one major river system, the region is at risk of further drying and latitudinal shifts in rainfall systems as the climate changes. Farming communities and families are suffering, and that has consequences for community morale and for individual and family wellbeing and health-related behaviours.

4 Exposure to greater and more frequent extremes of **heat in the workplace** (e.g. outdoor workers in Australia, and a wider range of workers in low-income countries) pose little-understood risks to safety, health and economic productivity.

5 Immediate health 'co-benefits' should accrue to local populations from national and community **actions to abate climate change** – via cleaner air, more physical activity (fewer cars), greater social interaction, better home insulation. Can these be quantified?

6 Meanwhile, Australians also have a responsibility to help **elucidate the health risks** to people in the Asia-Pacific region. Explorations and bilateral initiatives are now beginning to occur in that arena, although mainstream funding-agency support is difficult to attract.

The unusual long term future dimension of climate change and its resultant risks pose a supreme test for humans, a test of our capacity to take radical actions on behalf of The Future. That is a big deal. We are, at base, a product of Darwinian selection – that dispassionate process that necessarily operates in the present tense, accepting or discarding variant individuals according to their 'fitness' in the existing environment. For us to be here today, our ancient ancestors had to have been good at surviving their present tense. Yet global climate change is, principally, about surviving the future. A better understanding of the looming threats to health and survival will focus our collective mind on how to reach that future, sustainably, safely and socially cohesively. ■

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Professor Dorothy Scott

Professor Dorothy Scott is the soon-to-retire Foundation Chair in Child Protection and the Director of the Australian Centre for Child Protection at the University of South Australia. Before taking up this appointment in 2005 she was the Head of the School of Social Work at the University of Melbourne, and prior to that, the Executive Director of The Ian Potter Foundation. Dorothy spoke to *Australian Philanthropy*'s editor Louise Arkles.

How important is it for philanthropy to consider, and attempt to measure, wellbeing?

From a child protection perspective, emotional and social wellbeing is absolutely central. Not just the physical or emotional wellbeing of the individual, but the wellbeing of the family group, so the family has a sense of cohesion, identity and a future orientation. It's this future orientation which allows parents to make sacrifices; to save money, to put energy and effort into their child's literacy. Unless families have sufficient morale – and the supportive web of social relationships to sustain that – then we are more likely to see that family falling behind and possibly the children needing care.

If we look at families where child abuse and neglect occurs – particularly child neglect, which is the most common form of child maltreatment – mostly there are very deeply demoralised families, often with chronically depressed parents, often misusing substances. In fact two thirds of children who enter state care come from families where at least one parent has a drug and alcohol problem.

From a prevention point of view, understanding the sources of emotional and social wellbeing is vital. We often focus on trying to understand the problem, without first establishing what constitutes a healthy situation. Take incest for example – we don't spend much time reflecting on why, in the vast majority of families, the incest taboo is strong and remains intact. Unless we understand how this taboo is internalised so deeply that it becomes unthinkable to break it, then we can't grasp what happens in those families where that mechanism fails. Similarly, we need to research the biological, psychological, and social processes that form healthy, deep and secure attachments between parents and their children, because that's the most protective factor for child abuse and neglect.

So research is one of the keys to progressing child protection, and one in which philanthropy can play a major role, funding the intellectual capital which will take our response to child abuse and neglect forward in the same way as other major public health issues. An example close to my heart is that the Chair in Child Protection from which I am retiring only has funding for a few more years. I would therefore love to see a philanthropically funded Endowed Chair of Child Protection here at the Australian Centre for Child Protection focused on research utilisation, that is, taking research and translating it into policy and service delivery.

There's not a strong connection in the public consciousness between child abuse and neglect and prevention, in a health sense. Why is that?

To date, the history of child protection has been largely driven by philosophy and by supply and demand. It hasn't been underpinned by a rigorous evidence base, such as the Carnegie Foundation tried to instill in public education in the States, or Australian philanthropy supports in medical research. My passion is to nurture the knowledge base around child abuse and neglect, so we can apply a similar level of rigour to prevention and intervention in what was described in *The Lancet* as 'one of our biggest paediatric public health challenges'.

This is true for if you look at the research showing the long term health outcomes, both physical and mental health, of adults who suffered child abuse or neglect as children – in addition to the suffering it brings children in the here and now – it would have to be seen as one of the major pediatric public health challenges, yet it receives very little research funding.

“...we haven't conceptualised the problem of child abuse and neglect as a public health problem. Once one conceptualises it like that, then the knowledge-driven responses become so obvious. We don't even have to call it public health – we could tackle it like we did road trauma.”

Is that because we're very good at putting the ambulance at the bottom of the cliff, but not at putting the money into prevention?

We don't usually think of child abuse and neglect in terms of preventative health, but when we think of leukaemia, or type 1 diabetes, we are very keen to put philanthropic dollars into research way back from the edge of the cliff – and not just in terms of supporting high quality treatment.

It's because we haven't conceptualised the problem of child abuse and neglect as a public health problem. Once one conceptualises it like that, then the knowledge-driven responses become so obvious. We don't even have to call it public health – we could tackle it like we did road trauma. How did we achieve the most extraordinary success in reducing the road toll? We researched and understood the multiple contributing

factors: car design; road design; driver behavior, including drink driving; and then addressed each of these sets of factors and underpinned them by very rigorous research.

How might such strategies translate into preventing child abuse and neglect?

When you realise that 13 per cent of children in Australia are living in households with at least one adult who is regularly binge drinking, and that 50 per cent of children coming into care for the first time have at least one parent with an alcohol problem, then the single biggest challenge to preventing child abuse and neglect in Australia today is reducing the level of parental alcohol misuse.

Experts across a range of fields are calling for population-based measures to tackle child abuse and neglect at the source, by addressing parental alcoholism. Strategies like volumetric taxing of alcohol, bans on alcohol advertising, reform of licencing laws, and public information campaigns – where the message is that ‘drinking alcohol and caring for children don’t mix’ – have great potential to change behaviour. We need to shift the social norms so just as drinking while driving is regarded as socially irresponsible and negligent, it’s unacceptable for children to be exposed to intoxicated parents.

“Yes, we already know some of the answers, but taking this forward into the political domain, when you face the power of the liquor industry, is a major challenge. It raises interesting challenges for philanthropy around advocacy and social change.”

It sounds like there is strong evidence for change?

Yes, we already know some of the answers, but taking this forward into the political domain, when you face the power of the liquor industry, is a major challenge. It raises interesting challenges for philanthropy around advocacy and social change. The knowledge might be there, but it’s closing the gap between what we know and what we do that is the challenge.

What are the stand-out successes in philanthropic support for child protection?

The most recent example I’ve seen is the Children’s Protection Society’s new Child and Family Centre in Heidelberg West (Victoria), where the Integrated Early Education and Care Project will be trialled, to which The Ian Potter Foundation and The Myer Foundation have each contributed as well as the Australian Government. While the idea of creating specialised child development and care for vulnerable children, which is also therapeutic for their highly fragile parents, is not new, it hasn’t been tried in this way in Australia before. Essentially the vision is to create an environment with staff highly skilled in early childhood, working with very vulnerable families, engaging therapeutically with both child and parent. So the focus is not just on the child’s play, language skills and nutrition for example, but also on the parent-child relationship and trying to nurture any positive elements and address any dysfunctional dimensions in that relationship.



Another inspiring example was The R.E. Ross Trust’s support for the Nobody’s Clients Project run by Odyssey House in Victoria. With that support Odyssey House pioneered ways of working in an alcohol and drug rehabilitation centre which were mindful of the fact that most of their clients are parents, and their children are facing great disadvantage and are at high risk of developing their own mental health and social problems. Their transformative approach is very family centered; trying to tap parental motivation that comes from the children; trying to understand how the stresses of parenting with a substance dependence can actually cause relapse; trying to provide a therapeutic response to children who have already been harmed by their parents’ substance misuse; trying to normalise the opportunities in those children’s lives so that they might join a local soccer club or pursue a hobby, opening those children to the normal social networks in a local community.

In your speech at the 2005 Philanthropy Australia conference you argue that the model of innovation-evaluation-dissemination- replication is the most appropriate for philanthropy. Has anything changed, or do we still elect to do the seed funding, nurturing innovation, but neglect to disseminate learnings and replicate successful projects?

It’s important for philanthropy to see the whole of that process. If you focus just on fostering innovation, you can let a thousand flowers bloom but you may end up with a paddock full of petals, with just one or two that are cost-effective and transplantable innovations with the potential to be ‘scaled up’. Helping those that are standouts to succeed, by not only supporting the initial innovation but supporting a very rigorous evaluation of that innovation, and then supporting the dissemination of that approach – and then supporting attempts to replicate or adapt that model into different contexts – that is maximising the impact of your philanthropic dollars. It’s about staying with your project long enough to make sure its roots are deep in the soil and it has secured its own future, and influenced the wider field. ■

Viertel Charitable Foundation leading the way

By **Teresa Zolnierkiewicz**, Head of Philanthropy, ANZ Trustees.

The Sylvia and Charles Viertel Charitable Foundation generates income in the order of \$10 million per annum, giving to medical research, and health and wellbeing. In developing the giving program trustees focused on developing leadership of individuals, leadership of medical research organisations, as well as taking into account the special needs of the ageing and disadvantaged in rural Queensland.

Charles Viertel, the Foundation benefactor, was a Queenslander who left a large fortune for charitable purposes in his will. He died in 1992. The present Trustees of the foundation are: Mr George Curphey OAM, Mr Rex Freudenberg, Justice Debra Mullins and ANZ Trustees.

The Trustees honour Charlie's wishes by giving significant annual support to two leading medical organisations that Charlie favoured: The Queensland Eye Institute (at the Prevent Blindness Foundation) and The Viertel Centre for Research in Cancer Control (at the Cancer Council Queensland). This Centre demonstrates what can be achieved with core support over a few short years. The Centre has been able to grow its competitive grants tally from \$467,000 per annum in 2004, to \$2.43 million per annum in 2008. The focus of the Centre's work is on melanoma and prostate cancer as well as developing programs of psychosocial care and translating research into practice.

The Viertel Senior Medical Research Fellowships (VSMRFs) were established in 1995. Awards are made annually to two outstanding researchers with recognised postdoctoral achievements who are seeking to establish research careers in Australia. The awards are highly competitive, assessed by a special panel of experts, and are valued at \$975,000 each. To date 27 fellowships have been awarded.

A recipient of the Fellowship commencing in 2007 and working at the John Curtin School for Medical Research in Canberra, Dr Carola Vinuesa is a world leader in auto-immunity and immunology. Dr Vinuesa was recipient of the Prime Minister's Science prize in 2008 for Australian Life Scientist of the year. She was also awarded the Australian Academy of Science 2009 Gottschalk Medal which recognises outstanding young researchers in Australia.

The two most recent Viertel Fellowship recipients are Associate Professor Katie Allen, to research peanut food allergy in infants (Murdoch Children's Institute), and Dr Kieran Harvey, to explore how deregulated size control can be treated in human diseases such as cancer (Peter MacCallum Cancer Institute).

The Viertel Foundation giving program also includes:

- five clinical investigator awards per annum (\$60,000 each);
- PhD scholarships in Alzheimer's Research (\$180,000 per year);
- diabetes research grants (\$300,000 per year);
- a major investment in organisations supporting aged Australians in rural and regional Queensland, including Blue Care, RSL Care and Alzheimer's Australia Queensland; and
- support for the Leukemia Foundation.

The Foundation has not to date undertaken evaluation of its giving as it is wary of such a costly undertaking, however, it is in the process of preparing a history of the Foundation and its giving to be published in 2012. ■



MS research targeting prevention

By **Jeremy Wright**, Executive Director, MS Research Australia.

Every day another five Australians are diagnosed with multiple sclerosis (MS) – a lifelong and chronic disease, affecting 20,000 Australians, for which a cure has not yet been found. Symptoms vary from person to person and may include extreme fatigue, impaired vision, difficulty walking and in severe cases, partial or complete paralysis.

But there is hope – research into MS is achieving breakthroughs and holds the promise of better diagnoses and improved treatments, together with prevention strategies and ultimately a cure for this unpredictable disease. MS Research Australia

(MSRA), the national research arm of the state-based MS Societies, is coordinating, funding and accelerating this research, in partnership with medical research institutes around the country.

One of MSRA's major supporters has been the John T Reid Charitable Trusts, who provided an initial grant in 2006 for research into the genetics of MS. This support enabled MSRA to obtain a successful Linkage Grant from the Australian Research Council, funding a major three year project involving the collaboration of 11 Institutes around Australia and New Zealand, in what became known as the ANZgene project.

Macquarie Group Foundation Chair of Schizophrenia Research

By **Anna Le Masurier**, Macquarie Group Foundation.

One of Macquarie Group Foundation's driving beliefs is that a problem is best solved by first understanding its causes. With health problems in particular, significant financial resources are required to ensure appropriate research takes place to identify their triggers.

Research is thus a critical component of the Foundation's program of community support, as is supporting Macquarie staff in their community activities.

These two objectives dovetailed well with the establishment of the Macquarie Group Foundation Chair of Schizophrenia Research in 2006. The Foundation prioritises support to community organisations where there is a relationship with Macquarie Group staff. As the chairman of the Schizophrenia Research Institute (SRI) is Macquarie Banking and Financial Services Group Head Peter Maher, there was a clear opportunity to satisfy the two goals.

By providing funding for a Chair of Schizophrenia Research, the Foundation was not only able to support Peter's commitment to the SRI but could also contribute to a mental health disease that can struggle to attract a profile. This is despite the fact it ranks among the top 10 causes of disability in developed countries worldwide.

Head of the Macquarie Group Foundation Julie White explains that the Foundation's approach is one of engaged philanthropy beyond the simple provision of financial support. "With a senior Macquarie Group staff member on the SRI Board, we are connected in a very significant way to a research institution that may not as easily attract the same level of corporate support as other research bodies."

"When we were working with the SRI to determine the best funding approach, we decided to establish the only chair of schizophrenia research in the world because we saw it as an innovative way to make an impact on a disease which affects approximately one in 100 people globally. This support for innovation is also a way to reflect Macquarie Group's own goals and values in the not-for-profit sector."

The Foundation believed making such a large investment – Macquarie contributed \$1.375 million to the Schizophrenia Research Institute as part of a collaborative effort by the Institute and Neuroscience Research Australia, University of New South Wales (UNSW) and NSW Health – would send a signal to other funders about the importance of prevention, diagnosis and treatment of schizophrenia.

This turned out to be the case with the NSW Government's \$3.5 million funding to the SRI for the Macquarie Group Foundation Chair of Schizophrenia Research since it was established.

World renowned research Professor Cyndi Shannon Weickert was appointed the inaugural Chair. Cyndi's work focuses on molecular biology of growth factors related to schizophrenia and brain development and her team is now part way into a three-year clinical drug trial examining a faulty brain receptor identified in people suffering schizophrenia. ■



In mid 2009 the ANZgene project published the ground-breaking discovery of two new MS 'gene loci', which will help unravel the causes of MS. There has since been further funding from the NHMRC, and the ANZgene discovery has been recognised as one of the 'significant recent international contributions to MS research' by the prestigious scientific journal *Nature*.

Meanwhile another MS study, the AUSimmune project, was identifying environmental contributors to MS. The Australian National University researchers, supported by Vincent Fairfax Family Foundation, published their findings in 2008, with emphasis on Vitamin D deficiency as a potential factor in an individual developing the disease.

With the findings from these two projects 'converging', MSRA has now initiated a major new MS Prevention Trial. This is the first of its kind anywhere in the world, and will implement oral

Vitamin D supplementation for patients displaying the first signs of MS. If effective, this could provide a new low cost MS therapy with virtually no side effects.

This example highlights the terrific impact that philanthropy has had assisting ongoing MS research, and enabling Australian scientists to contribute significantly to the world-wide effort to solve this disease. ■

www.msra.org.au



Mobiletype – mobile technology impacting health

By **Stacey Thomas**, National Coordinator, Telstra Foundation Community Development Fund.

With a mission to make a positive and lasting difference to the lives of Australian children and young people, the Telstra Foundation supports projects that have a direct impact on the health and wellbeing of recipients. One project, Mobiletype, stands out as delivering direct health and wellbeing outcomes to young people through an innovative use of technology.

Mobiletype is a tool developed to detect, treat and manage adolescent mental health. Identifying that 30 per cent of young people will experience some form of depression by their late teens, the team at Murdoch Childrens Research Institute developed a technology-based application to assist GPs to detect, prevent and treat mental health problems in young people.

Under the lead of Dr Sophie Reid at the Murdoch Childrens Research Institute, the Mobiletype program uses mobile phones to interact with young people and assess things like mood, stresses, coping strategies and eating patterns of young people. It does this by asking participants pre-determined questions which can then be easily answered via text message throughout the day. The process is quick, private and non-invasive and, given the way most young people use mobile phones every day, a very natural form of communication.

Their responses interact with a web interface which collates them, and allows GPs to access individualised reports about their young patients. These reports are used as the basis for recommendations for intervention strategies and referrals, drawing upon best practice principles in the treatment and management of adolescent mental health.

“One of the key pieces of feedback that we get from young people is that they feel like their doctor really cares about them, and they are pleased to share this detailed information with their doctor.”

Dr Reid explains “One of the key pieces of feedback that we get from young people is that they feel like their doctor really cares about them, and they are pleased to share this detailed information with their doctor.” In previous studies over 90 per cent of young people report an increase in insight into their problems and 82 per cent report that they feel their doctor understood them better for using the Mobiletype program.

Mobiletype is a worldwide first using mobile technology to track mood, behaviours and the daily experiences of young people. It has received significant support from Telstra



Mobiletype in action.

Foundation and the greater philanthropic and corporate communities as well as government. Collaborators on the project have included Harvard Medical School, and the Department of General Practice University of Melbourne.

Currently completing a randomised control trial, preliminary research has shown that Mobiletype is a much needed service, particularly for those who have previously found it difficult to get help such as young people in rural settings. Full research results will be available at the end of 2010. ■

www.telstrafoundation.com



Life changing research in Western Australia

By **Jan Stewart**, Lotterywest.

Lotterywest, established in 1932 to operate the Western Australia (WA) state lottery in order to raise money for the charitable and community groups of our state, has a proud history of supporting medical research in WA.

Since 1992 when we set up our first specific program to fund medical research, Lotterywest has provided grants totalling almost \$36 million to support medical research, including a major grant of \$5.4 million made by the board only last month. Funds have been used primarily for significant, 'cutting edge' facilities and research infrastructure which can be shared by all Western Australian researchers.

Highlight projects include the WA micro-array facility, which supports leading genetic research and a major investment in the state's biotechnology platform.

"These facilities, along with many others, are serving to attract world class researchers and leverage considerable investment which has ensured that the medical research in WA remains competitive and globally relevant."

These facilities, along with many others, are serving to attract world class researchers and leverage considerable investment which has ensured that the medical research in WA remains competitive and globally relevant.

Key examples of outcomes achieved as a result of Lotterywest support include:

- The Western Australian Institute for Medical Research has achieved research breakthroughs using sophisticated equipment supported by Lotterywest grants, including identifying new genes affecting cancer and leukaemia patients, an important discovery on the blood vessels that circulate around tumours, and successfully animal-tested a cure for the devastating muscle disease that causes 'Floppy Baby Syndrome'.
- Burns specialist and former Australian of the Year Professor Fiona Wood has extended the invention of spray-on skin and developed appropriate psycho-social treatments for burns patients to ensure a holistic approach to supporting their return to family and community life.
- Professor Simon Mallal, from the Institute for Immunology and Infectious Diseases based at Murdoch University, has developed a genetic test to identify patients at risk from the problematic anti-retroviral drug for HIV AIDS.



Professor Simon Mallal.

- Current Western Australian of the Year, Professor Ralph Martins was the first to discover the 'beta amyloid protein' coating on the brain as the foundation of Alzheimer's disease. New research facilities will house the latest technology that will determine if people are 'at risk' and will work towards developing an early stage diagnostic blood test.

Beyond the advancement of medical outcomes, Lotterywest provides grants in a way that ensures the shared use of the infrastructure by as many researchers as possible. This is enhanced by the collaboration not only between researchers but also between research bodies around the shared ownership and management of the range of facilities that have advanced medical research in WA.

Finally, in supporting the establishment of buildings, space is provided for community organisations so that communication and collaborations between researchers, practitioners, community support groups and the general public can occur. Here they can come together to understand and learn from one another; engage in debate about important issues, research priorities and ethical challenges; and create opportunities for effective translation and application of research. ■

www.lotterywest.wa.gov.au



Supporting medical research

By **Dr Noel Chambers**, Director Philanthropy, Research Australia.



Philanthropy is an important source of support for health and medical research around the world. Effective research depends on investment from government, industry and the community: a strong pool of philanthropic dollars for health and medical research has the potential to boost our national capability to address health challenges.

A 2005 study by Queensland University of Technology, commissioned by Research Australia, found that:

- leading nations have research supported by multiple sources, including government, industry and philanthropy;
- philanthropic funding can address gaps in other funding sources, including high risk investments, rare diseases and global health issues; and
- philanthropic funding generates an increase in funding from government and industry sources.¹

Yet philanthropic support for health and medical research in Australia is not strong. In 2006, Research Australia published 'Health and Medical Research Philanthropy: the Fourth Dimension of the Virtuous Cycle' which showed that philanthropic support for research was low by international standards, especially compared to the US, and also low compared to giving to other causes. The average yearly donation to medical research, according to Giving Australia, was \$77, compared to religious or spiritual organisations (\$529), international aid and development organisations (\$234) and arts/cultural associations (\$220).²

More recently, the Research Australia Public Opinion Poll 2008 surveyed the community on a number of issues relating to health and medical research philanthropy, including the number of donations per year, average annual donation and recipient organisations. The average donation had risen to \$101 per annum. However, nearly three quarters of Australians (73 per cent) give less than \$100. Larger donations are less common, with only 14 per cent

donating between \$101 and \$500 a year and just 2 per cent giving more than \$500 a year.

Lifting philanthropic support for health and medical research is an important priority for all Australians, particularly given the wide-spread concern about affordability of health care, and our aging population. Such research has delivered many tangible benefits to the community, including the Bionic Ear, the cancer vaccine Gardasil, the antiviral drug Relenza, and a new paradigm for the treatment of ulcers with the Nobel Prize winning work of Professors Barry Marshall and Robin Warren.

Some recent examples that have direct impact upon individuals, families and their employers include:

- beyondblue invested \$3.7 million into a five year (2002-2005) national postnatal depression screening study that involved 40,000 pregnant women and 12,000 new mothers, across 43 health services. The results showed 16 per cent of women in Australia experience postnatal depression. As a result of recommendations from beyondblue the Commonwealth Government contributed \$55 million to a five year National Perinatal Depression Initiative (NPDI), with an additional \$30 million from State and Territory Governments.
- beyondblue has also led the development of the Australian-first National Health and Medical Research Council endorsed Perinatal Clinical Practice Guidelines designed to guide health professionals in the assessment, treatment and management of depression and related disorders in women, pre and postnatally.
- Dr Natalie De Morton was awarded a grant of around \$100,000 between 2005 and 2007 from the HCF Health and Medical Foundation to develop the first mobility instrument (the DEMMI) to accurately measure and monitor the mobility of older people. Already widely implemented in clinical practice, the DEMMI is being taught in undergraduate Physiotherapy curricula in Australian universities, and translated into seven different languages.

When thinking about supporting medical research, the flow-on benefits of a single grant are often not apparent. A more effective drug treatment not only improves the quality of life of the patients and their families, it can also reduce hospital admissions or length of stay, reduce hospital waiting lists, and ultimately place downward pressure on insurance costs. Consequent reduced absenteeism in the workplace can contribute to workplace productivity and improved family income.

In 2009 Research Australia launched a new philanthropy initiative to connect grantmaking foundations and major donors with health and medical research projects in Australia. The Building Philanthropic Support for Australian Health and Medical Research initiative undertaken by Research Australia is supported by funding from the Australian Government Department of Health and Ageing.

Research Australia is a national alliance of over 190 organisations, with a mission to make health and medical research a higher national priority. Independent of government and not-for-profit, Research Australia's activities are funded by its members, donors and supporters from leading research organisations, academic institutions, philanthropy, community special interest groups, peak industry bodies, biotechnology and pharmaceutical companies, small businesses and corporate Australia. ■

1. Lifting the Lifegiving Dollar – Prepared by Queensland University of Technology for Research Australia, 2005.
2. Giving Australia: Research on philanthropy in Australia, Australian Government, 2005.

www.researchaustraliaphilanthropy.org

Research Australia

An alliance for discoveries in health

Bupa Health Foundation – from little things, big things grow

By **Teresa Howarth**, Health Partnership Manager, Bupa Health Foundation.

Much has been said in relation to the philanthropic landscape and donation trends in Australia, particularly as they relate to investment in health. When the MBF Foundation – now the Bupa Health Foundation – was established in 2005, its fundamental purpose was to make a real difference to the health of our community now and into the future. Realisation of this goal is undertaken through:

- investment in world leading research;
- advocating for key health issues; and
- improving the health of our community.

Five years on, as one of the largest sources of corporate giving dedicated to health in Australia, the Bupa Health Foundation has made a combined investment of over \$14 million in around 50 partnerships across the national health industry, with key areas of focus aligned with major population health challenges of wellness and obesity, healthy ageing and keeping healthcare affordable.

Some of these partnerships have already produced exciting, tangible results and outcomes. The National Pain Strategy is one recent example. The Foundation's work in this area initially involved commissioning of the MBF Foundation report "The High Price of Pain", conducted by Access Economics using data from the Pain Management Research Institute, which estimated the cost of pain in Australia at \$34.3 billion. This report highlighted the need for chronic pain to be elevated as a health priority and made a number of recommendations for this. The National Pain Strategy has subsequently been developed as a first step in progression of these recommendations.

The Foundation also supports the extraordinary work of the Centre for Eye Research Australia which is using retinal scans as a non-invasive, early detection tool to predict whether a patient may develop cardiovascular disease and stroke.

Earlier this month, Bupa Health Foundation proudly announced eight new partnerships which have the



Recipients of Bupa Health Foundation 2010 Health Partnership Awards, announced on 16 June 2010.

potential to positively influence the health outcomes of our community now and into the future.

- Cancer Council Victoria – 'Effects of counter-advertising on parent/child susceptibility to junk food promotions'.
- Monash University/Southern Health – 'Application of integrated disease self-management in type 2 diabetes mellitus'.
- Baker IDI Heart & Diabetes Institute – 'Evaluation of long term maintenance of community-based strength training'.
- Cooperative Research Centre for Oral Health Science – 'Multimedia Web Enhancement Oral Health Promotion Program for Older Adults'.
- Brain & Mind Research Institute (University of Sydney) – 'The Beyond Ageing Project'.
- Cabrini Hospital – 'Health Outcomes in Elderly Patients following Cardiac Surgery'.
- St John of God Health Care/University of NSW – 'Perinatal mental health assessment: does it improve maternal health outcomes?'.
- James Cook University – 'National Small Abdominal Aortic Aneurysm Trial'.

Advocacy initiatives

Additionally, the Foundation continues to support, promote, and actively participate in advocacy associated with significant health challenges affecting our community. One of the most significant health issues impacting upon all Australians is mental health. The prevalence of mental illness is such that all of us will have been touched

by it in some way – whether through a family, friend, colleague or neighbour. 75 per cent of adult mental health disorders are present before the person reaches 25 years of age and, alarmingly, one million young Australians (some as young as 12 years old) are suffering from emerging mental health disorders.

Within this advocacy role, Bupa Health Foundation has recently formed a strategic partnership with headspace, Australia's National Youth Mental Health Foundation, to raise awareness and boost advocacy efforts for young people with mental health issues. Bupa Health Foundation is also proud to support the first International Youth Mental Health Conference in July 2010, and a series of forums which will bring together politicians, policy-makers, academics, health care providers, multidisciplinary healthcare practitioners and the community.

Bupa Health Foundation's investment is directed to partnerships that make a difference through applied clinical and health science research, seed funding in support of proof-of-concept studies, educating the community in health or investing in community programs that impact on policy and practice. Together with our partners, the Foundation is developing a reputation for innovative and pioneering work which will truly make a difference in the important objective of building a healthier Australian community. ■

www.bupa.com.au/foundation



What's next for philanthropy

This snapshot, which accompanies the full report, executive summary and innovation toolkit produced by the publishers, is generously made available with a Creative Commons licence by the Monitor Institute. They can all be downloaded from <http://www.monitorinstitute.com/whatsnext/> or contact whatsnext@monitor.com

Acting bigger and adapting better in a networked world

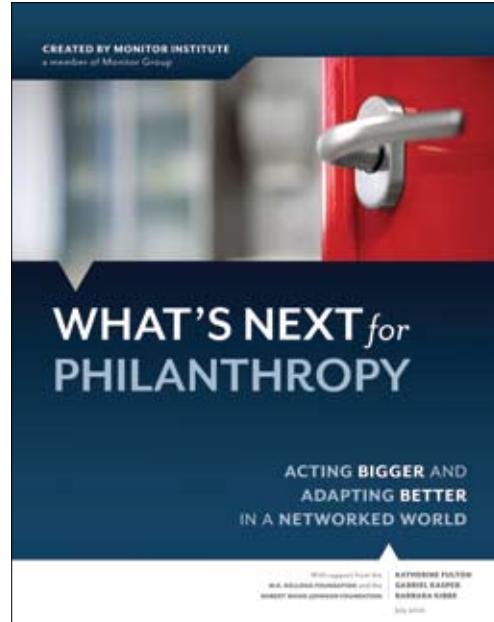
Philanthropy today takes place in a context that is radically different from the environment in which many of its current practices and behaviors were developed.

An intimidating range of forces – globalization, shifting sectoral roles, economic crisis, and ubiquitous connective technologies, to name just a few – are changing both what philanthropy is called upon to do and how donors and foundations will accomplish their work in the future.

Yet many of philanthropy's core practices and principles remain essentially unchanged from the way they were done a hundred years ago, when Andrew Carnegie and John D. Rockefeller first created the foundation form. The world around philanthropy is changing much, much faster than philanthropy itself.

This is not to say that philanthropy hasn't responded to the shifting landscape. To the contrary. As the relevance and role of philanthropy has become a more urgent question over the past decade, newer actors and older institutions alike have been striving to be more strategic, efficient, and effective in a variety of ways. But it is clear that the last decade's changes will not be sufficient.

The new context requires that funders adjust to the ways in which their actions are connected to others' actions, in a dynamic interplay with external events, in order to have a greater impact, faster.



Where the cutting edge of philanthropic innovation over the last decade was mostly about improving organizational effectiveness, efficiency, and responsiveness, we believe that the next practices of the coming 10 years will have to build on those efforts to include an additional focus on coordination and adaptation. The most innovative funders in the future will do more than operate as effective, independent institutions. They will act BIGGER and adapt BETTER:





Next practices for philanthropy's next decade

Simply tweaking the status quo is not likely to be enough for philanthropic and civic leaders looking to cultivate change more effectively in a world that sorely needs it. Tomorrow's most successful funders will do more than just adopt today's best practices. They will have to pioneer 'next practices' – new ways of working that fit the emerging landscape of public problem solving:

Acting BIGGER

1 Understand the context

Strong peripheral vision – seeing and developing a shared understanding of the system in which they operate – will be critical to helping funders build and coordinate resources to address large, complex problems.

RE-AMP, a collaborative of Midwestern foundations and nonprofits, developed a shared understanding of the levers for achieving clean energy in the Midwest by mapping the system of relevant forces and players, helping to align the vision and coordinate the efforts of many independent stakeholders.

2 Pick the right tool(s) for the job

Funders have a wide range of assets – money, knowledge, networks, expertise, and influence – that can be applied deliberately to create social change.

The Vermont Community Foundation is ensuring that its investment strategies complement its programmatic goals by offering donors the option to invest money in local socially-responsible businesses, using its investment managers to vote by proxy, and co-filing activist shareholder resolutions.

3 Align independent action

Philanthropies are developing new models for working together that allow for both coordination and independence. Funders don't necessarily need to make decisions together, but they do need their efforts to add up.

The Climateworks Foundation has helped more than 10 funders and scores of other actors work in concert as part of a \$1 billion coordinated global campaign to fight climate change by addressing global energy efficiency standards, forest conservation and agriculture, and low-carbon energy supply.

4 Activate networks

Advances in network theory and practice now allow funders to be more deliberate about supporting connectivity, coordinating networks, and thinking about how the collective impact of all of their efforts can produce change far beyond the success of any single grant, grantee, or donor.

The Barr Foundation is building a stronger network of afterschool service providers for Boston youth by supporting "network weavers" who facilitate relationship building, knowledge sharing, and collaboration among service providers and community leaders.

5 Leverage others' resources

Funders can use their independent resources as levers to catalyze much larger streams of funding and activity from other sources by stimulating markets, influencing public opinion and policy, and activating new players and assets.

The Clinton Health Access Initiative is working to aggregate demand, improve efficiencies, and reduce volatility in the market for AIDS drugs in an effort to provide medicine affordably in Africa and the Caribbean.

Adapting BETTER

6 Know what works (and what doesn't)

Effective funders will develop systems to learn from their successes, and their failures, in ways that can help everyone – funders and grantees alike – develop the judgment to guide and improve efforts in the future.

The Wallace Foundation is systematically testing and evaluating innovative educational and cultural programs around the United States, methodically sharing the results to broadly spread knowledge about effective approaches – with more than 200,000 report downloads a year.

7 Keep pace with change

As the speed of change accelerates around us, funders will need to build feedback loops that help them change and shift behavior based on dynamic realities and lessons learned in real time.

The Rockefeller Foundation has replaced its long-standing, fixed "programs" with a set of interconnected, time-limited "initiatives" that aim to allow the Foundation to quickly respond to unanticipated opportunities, to shift tactics when necessary, and to regularly recalibrate its approach to fit external needs.

8 Open up to new inputs

New tools and approaches now allow funders to solicit points of view from diverse cultures and perspectives, to access new and wildcard ideas, and to get buy-in and engagement from stakeholders.

The Center for Effective Philanthropy's Youthtruth initiative is measuring the success of school reform by soliciting feedback directly from high school students about the quality of their experience, providing valuable input to foundation and district leadership from voices that would normally not be heard.

9 Share by default

In a more crowded playing field, there is tremendous value in reflecting on your work and conveying your lessons to others. It makes sense to start from a place of sharing everything and then make a few exceptions, rather than a place of sharing little where transparency is the exception.

Ashoka's Changemakers competition "open sources" proposals by placing them on a public messageboard, allowing the community of participants to not only choose their favorites but also to strengthen all of the contestants' ideas and build awareness of them in the field.

10 Take smart risks

The most effective funders will recognize when innovation is necessary, and will be willing to make high-risk, high-reward bets that have the potential to create transformative change.

The Heinz Endowments, the Grable Foundation, and the Pittsburgh Foundation took the risk of abruptly and publicly cutting funding to the city's failing school district in order to spark the public engagement necessary for reform.

The MJD Foundation – more than a health promotion charity

By **Nadia Lindop**, Executive Officer, MJD Foundation.

In 2008 the MJD Foundation was established and we ticked the 'Health Promotion Charity' box on the ATO's deductible gift recipient application form. This seemed straightforward. Machado Joseph Disease is a health issue and particularly an Indigenous health issue in Australia, and our mission was clear: "to improve the quality of life for Indigenous Australian Machado Joseph Disease sufferers and their families in Arnhem Land and beyond".

What seemed like a simple choice has proven to be complicated. Complex and multi-tiered political structures; and language, cultural and geographical challenges associated with remote living are just some of the barriers that exist in achieving improvements in Indigenous health and for sufferers of MJD.

What is Machado Joseph Disease?

MJD is a hereditary neuro-degenerative condition which occurs because of a fault in a gene which causes too much of a particular protein in the brain. This slowly kills off nerves, which leads to muscular weakness, which then progresses to a lack of voluntary control and significant permanent physical disability. There is no cure for MJD. Progression to dependence occurs over five to 10 years and most people are wheelchair bound and fully dependent for activities of daily living within 10-15 years of symptom onset.

Whilst MJD occurs internationally, the prevalence of MJD amongst the Indigenous population of the Northern Territory is the highest in the world at 100 times the international average.

A holistic approach to Indigenous health

The MJD Foundation is a Health Promotion Charity, yet since 2008 we have sought to solve issues such as these few examples below:

- A Groote Eylandt woman was wheelchair bound, yet had no ramp on her house. The political complexities at the time made it impossible to determine who, if anyone, was responsible for building the ramp.
- An Elcho Island woman decided to be tested for MJD. Her doctor crossed paths with her at the airport and told her she was positive for the disease. She had no access to counselling, no understanding of the disease or what she could do to stay strong. The next scheduled visit by the medical geneticist was eight months away.
- A Groote Eylandt man with advanced MJD lives in a house that is crowded with 19 people in three bedrooms. His carers cannot get any sleep, and struggle to keep up with everyday activities including washing his sheets due to his bladder incontinence issues.
- In many remote communities, the only viable means of transport is by aircraft, and the indignity of being carried up and down aircraft stairs is unbearable.



MJD Foundation's Simone McGrath helps Warren Lalara demonstrate the new aircraft wheelchair lift at the June 2010 launch in Darwin. Photograph by Kate Freestone.

Improving health is a broader canvas than just those high profile activities such as medical research, treatments, and therapies. A more inclusive approach to funding Indigenous health is needed, that includes education, infrastructure, equipment, housing and cultural awareness. As well, it is essential to tackle the barriers to service providers around complex issues concerning kinship, language and the physical remoteness of communities.

What does the MJD Foundation do?

The MJD Foundation has established research programs for sleep disturbances, bladder incontinence, speech/swallowing difficulties, and a treatment for MJD. We supplement government genetic services and provide translated education tools. We purchase medical equipment and other items which are not available under government schemes. We are improving services by implementing an MJD therapy program, improving travel options, establishing a mental health program and developing MJD medical protocols. We advocate for our clients by working with employers, other agencies to ensure equality of opportunity and seeking improved government services.

Improving Indigenous health and wellbeing is not easily categorised into one box on a form. A holistic approach is essential in making a real difference to individuals and communities. Whilst improved medical services and medical research are essential in tackling any disease, the full range of support needed for individuals, their carers and communities living with chronic disease is extensive and pervasive. There is much scope for philanthropy to assist, and to make a real difference in Indigenous health. ■

For more information on Machado Joseph Disease and the MJD Foundation visit www.mjd.org.au



Members of Philanthropy Australia

New Members

Philanthropy Australia would like to warmly welcome the following new members:

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Bjarne K Dahl Trust
E. Dean
ING Foundation
Lorenzo & Pamela Galli Charitable Trust
Mirboo North & District Community Foundation
Origin Foundation
The Palya Fund
The Paul Griffin Charitable Trust
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Intensive Care Foundation
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nib Foundation
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Sparke Helmore Lawyers
C. Spence
F. Spitzer
The Stan Perron Charitable Trust
Stand Like Stone Foundation
State Trustees Australia Foundation
Sunshine Foundation
Sydney Community Foundation
Tasmanian Community Fund
Tasmanian Early Years Foundation
Telematics Trust
Telstra Foundation
Tessana Pty Ltd
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Three Flips Foundation
Tibetan & Hindu Dharma Trust
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Queensland Library Foundation
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Rural Health Education Foundation
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Spina Bifida Association of SA Inc
St. George Foundation
St Margaret's Foundation
St Mary's Cathedral Hobart Restoration
St Paul's Anglican Grammar School
St Vincent de Paul Society of Victoria
St Vincent's & Mater Health Services
Starlight Children's Foundation
The State Library of NSW
The State Library of Victoria Foundation
Stewart Partners
Surf Life Saving Foundation
Sydney Institute of Marine Sciences
Sydney Opera House
Sydney Theatre Company
Taralye

Travellers Aid Australia
UCA Funds Management
United Way Australia
University of Melbourne – Advancement and Communications Unit
The University of Melbourne – Alumni Office
University of New South Wales
University of Newcastle Foundation
University of South Australia Foundation
University of Sunshine Coast
University of Tasmania Foundation
VicHealth
Victoria University
Vision Australia
Volunteering Australia
Warakirri Asset Management
Western Australian Institute of Medical Research
Westmead Medical Research Foundation
Whale & Dolphin Conservation Society
Whitelion
Wise Community Investment
World Society for the Protection of Animals
World Vision
YMCA of Sydney
Youngcare
Youth Off The Streets



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