



**Queensland University of Technology**  
**Brisbane Australia**

CENTRE OF PHILANTHROPY AND NONPROFIT STUDIES

# Lifting the Lifegiving Dollar

Case samples of creative practice in  
health and medical research philanthropy

Prepared for:

**Research Australia**

An alliance for discoveries in health

2005

## Special Note

This study conducted by CPN QUT commissioned by Research Australia to explore international trends, experiences and present case examples of best practice in health and medical research philanthropy. It is a companion document to Research Australia's discussion paper, entitled Health and Medical Research Philanthropy: The Fourth Dimension of the Virtuous Cycle. Both documents are presented together as complementary resources to inform discussion relating to the need for a strategic approach to Australian philanthropy in health and medical research.

## Disclaimer

This report provides information as available at the time of production, drawn extensively on information provided freely by individuals, businesses, governments and other organisations. Research Australia and Queensland University of Technology do not guarantee the accuracy or completeness of the information provided and accept no liability for any errors.

## Copyright

© Research Australia 2005

This work including without limitation all information, text, names and logos is protected by copyright. This work may be used for your own personal use, information, research or study, or in a public forum solely for the promotion of health and medical research and philanthropy for health research, so long as the work is attributed to Research Australia and used in a strictly not-for-profit capacity. Reproduction by bona fide newspapers, journals and similar publications is also permitted by Research Australia subject to attribution of Research Australia in any reproduction. Neither this work (nor any part of it) may be reproduced, stored, on-sold, redistributed or otherwise used for profit.

# Contents

Special Note - Disclaimer - Copyright	1
Contents	2
Preface	3
Executive Summary	4
<b>1. Introduction</b>	<b>6</b>
1.1 Report Structure	6
1.2 Findings Overview	6
1.3 Scope	6
1.4 International Overview	7
<b>2. International Models of Philanthropy</b>	<b>8</b>
2.1 United States of America	8
2.2 United Kingdom	16
2.3 Singapore	20
2.4 Israel	23
2.5 Canada	25
<b>3. Australia Models of Philanthropy</b>	<b>27</b>
3.1 Giving Overview	27
3.2 Statistical Information on HMR Giving	28
<b>Bibliography</b>	<b>33</b>

# Preface

## 2020 vision

*An ideal 2020 vision for the funding of Australian health and medical research might feature ample government funding, a lively science base, dynamic commercialisation and thriving infrastructure. In this rosier landscape, Research Australia's (RA's) mission of elevating health and medical research on the national agenda would be flourishing and four out of five Australians would give routinely to health and medical research. High quality non-profit health and medical research charities would be so well respected and proactive that the field would be named in two out of five Australian wills. An upsurge in interest from high net worth individuals would see Australia approaching the UK situation of almost equal inputs from philanthropy and government. Heightened community interest and understanding would have been a force in winning and sustaining the ample, lively, dynamic and thriving funding situation above. ....Possible scenario or utopic dream? ....*

This study aims to stimulate thought, debate and action for change on this question of more vigorous philanthropic funding of Australian health and medical research (HMR). It sharpens the argument with some facts and ideas about HMR funding from overseas sources. It also reports informed opinions from those working, giving and innovating in this area. It pinpoints the range of attitudes to HMR giving, both positive and negative. The study includes some aspects of Government funding as part of the equation, viewing Government as major HMR givers, with particular ability to partner, leverage and create incentives.

Stimulating new philanthropy takes active outreach. The opportunity to build more dialogue between the HMR industry and the wider community is timely given the 'licence to practice' issues and questioned trust that applies currently somewhat both to science and to the charitable sector. This interest in improving HMR philanthropy also coincides with the launch last year by the Federal Government of Nonprofit Australia Limited (NAL), a group currently assessing infrastructure improvements to the charitable sector.

History suggests no one will create this change if Research Australia does not. However, interest in change exists in various quarters. For Research Australia to successfully change the culture of Australian HMR giving, the process will drive the outcomes. Obviously stakeholder buy-in and partners will be needed and the ultimate blueprint for greater philanthropic HMR funding here will not be this document. Instead it will be the one that wears the handprint and 'mindprint' of the many architects and implementers interested in promoting HMR philanthropy, from philanthropists to nonprofit peaks to government policy arms. As the African proverb says, 'If you want to go fast, go alone; but if you want to go far, go with others'.

# Executive Summary

## 1. The potential to create a climate for greater health and medical research funding exists in Australia.

- Research Australia is well positioned and well timed (though not necessarily yet well resourced) to spotlight health and medical research as a cause and stimulate further philanthropy. A successful model for this role exists locally in the arts sector (Australia Business Arts Foundation and ArtSupport). Greater national promotion of philanthropy has been building in recent years and health and medical research should be ready to capitalise on this heightened awareness and marketplace 'noise'. Similarly, significant research about Australian giving, donor attitudes and non-profit opportunities and capacity building needs has just been released through the 2005 Giving Australia research .

## 2. A critical mass of allies will be needed to advance the process - carefully. A consistent thread in this research is 'multi-stakeholder efforts' (eg. Research Canada).

- Potential allies for this process exist with whom dialogue can be initiated (such as Fundraising Institute Australia, Philanthropy Australia, relevant Government Departments and initiatives including the Prime Minister's Community Business Partnership, the Health Department/s and the National Health and Medical Research Council). Advocates for science funding and communication may also figure here. The literature across several nations emphasised the increasing complexity of medical research and its interplay with basic research in physics, chemistry, engineering etc.;
- Wider stakeholder discussions will be crucial. How can climate creation be funded and what strategic role does Research Australia take in this climate creation. Does Research Australia seek to grow the health and medical research philanthropic pie and by agreement with its members capture a sliver of that money to help fund its own activities? Alternatively, should Research Australia foster an umbrella foundation of its own (such as the SingHealth Foundation case in Singapore or the Foundation for Rural and Regional Renewal for rural causes in Australia, or the Australian Sports Foundation) and create another layer of giving?

## 3. Key landscape change that has been successful elsewhere features stronger health and medical research charities and specific resourcing of major givers.

- Key activities that RA and its allies could catalyse include:
  - strengthening the capacity, collaboration and voice of health and medical research charities/development offices (with the UK Association of Medical Research Charities as a starting point for thought here, and best practice models such as the National Kidney Foundation of Singapore). This may also be an appropriate area for a carefully crafted 'no strings' collaboration with pharmaceutical companies, some of whom have traditionally funded community support groups through their foundations.
  - resourcing philanthropists and their advisers to better understand and fund health and medical research (for example through collaboration with Philanthropy Australia to create a Health and Medical Research Affinity Group, through focus activities such as the US Foundation Center's Health Funding Month and through targeted campaigns to other emerging 'referral' points such as financial advisers to high net worth Australians).

## 4. A tailored venture philanthropy model may be worth consideration.

- Several models for venture philanthropy in medical research exist that may be adaptable to Australia (see US section: Goldman Philanthropic Partnerships and the Institute for the Study of Aging; also the Israel Venture Network as a nonmedical example);

## 5. Greater corporate funding may be possible in several ways, all of which take funding and effort to achieve.

- Corporate funding (ie. non pharmaceutical) for health and medical research has not been significant apart from some stellar trust and foundation examples (eg. UK's Wellcome Trust, US Howard Hughes Medical Institute and Gates Foundation). Conceivably a smaller but still significant Australian business star could emerge as a medical research champion through diligent research and negotiation. Given the potential return, such an exercise would be appropriate for RA to fund and facilitate, even if no Howard Hughes emerges at the end of the quest. The process may in fact locate a 'Giving Circle' of likeminded individuals of affluence and influence who may together make a significant funding impact and endowment (akin to the Smile Foundation concept profiled in the Australian section).
- The National Kidney Foundation of Singapore has captured the latest trend toward pledged regular monthly giving by signing up not only employees in Give as you Earn arrangements but also employers giving ongoing corporate gifts. Potential may exist, for instance, in the SME sector to do likewise in Australia through a targeted effort. Potential also exists to assist medical research charities to capture more corporate partnerships, similarly to the work of ABAF for the arts through workshops, networks and publications.

## 6. Greater communication between scientists and their philanthropic funders is identified as an issue by philanthropists and interviews indicate this improvement could lead to more ongoing funding.

- A major theme from the interviews with Australian philanthropists was the priority they place on good sustained relationships and feedback from funded scientists and their institutions. They recognise not all scientists will have a communication bent and place the blame with the scientific administrators. Although many organisations do have a strong science communication focus, there is clearly room for improvement.
- Direct feedback in workshops from philanthropists on their expectations and experiences is one strategy that may help (although some institutions may have such training already underway).

## 7. Few attitudinal barriers to giving to medical research have been reported.

- Health and medical research is seen as a logical destination for philanthropic funds for philanthropists without an exclusive passion to give elsewhere. Reasons cited for not funding medical research were fairly standard and included: 'the government should do it, there is so much duplication, our input is too small to make a difference, I don't know how to judge good science, it takes too long to see a return'. Philanthropists interviewed mostly gave to a range of causes with medical research one among them. Many but not all had a particular link to health issues through family. The question of intellectual property (IP) ownership for discoveries fully or partially funded by a philanthropist arose as one potential issue, rather than a barrier. Medical research funding was seen by some as 'harder work than other fields' (and for this reason less tackled by the trustee companies) but that was not seen as a reason not to fund it.

# 1. Introduction

Research Australia (RA) was established following the Wills Report, a strategic review of health and medical research (HMR) in Australia. As one plank of its strategic plan, Research Australia is focusing on philanthropic funding of HMR. Accordingly, Research Australia commissioned the Queensland University of Technology (QUT) Centre of Philanthropy and Non-profit Studies (CPNS) to conduct this study in February 2005.

## 1.1 Report structure

Following background sections, international comparisons are presented, opening with general information on the various countries' giving climates and infrastructures, then outlining where available any specific data on HMR giving. Snapshots of key players and successful models are then provided, be they philanthropic or HMR infrastructure that might support better philanthropy.

## 1.2 Findings overview

The study suggests a range of strategies and tactics for consideration by various stakeholders. Essentially the path forward is founded on three key actions:

- Distil the best possible ideas that might work well in Australia;
- Present and consult with different stakeholders on recommendations; and
- Galvanise a critical mass of allies to foster HMR philanthropy.

## 1.3 Scope

Information presented stems from a literature scan, web searches and personal or telephone interviews with:

- philanthropists to health and medical research;
- charities in this area;
- philanthropic industry peak bodies;
- philanthropic foundation representatives;
- academics studying the not-for-profit sector; and
- health and medical research industry peak bodies.

The study also draws upon the CPNS existing knowledge of philanthropic environments and of medical research giving.

The report does not claim to be comprehensive but rather indicative, painting the giving picture and identifying iconic, successful examples for idea takeouts to adapt to the Australian context.

Nations included in this study were selected to provide examples from a range of different size countries and perspectives. All countries included had varied giving climates, along with active and/or developing medical research sectors:

- United States of America (USA)
- United Kingdom (UK)
- Singapore
- Israel
- Canada
- Australia

It is important to note that philanthropy researchers generally recommend caution in international comparisons, given the lack of standard methods and definitions in collecting and reporting data. Accurate comparisons of giving and volunteering remain a challenge.

## 1.4 International Overview

The countries included in this study each have some distinctive approaches to health and medical research philanthropy, some resulting from organic and gradual development while others have implemented planned programs.

It has not been possible to construct international comparisons of data as health and research are not often separated within philanthropy data and measures vary across countries.

However - the themes of culture and government leadership have emerged as differentials across countries.

Notably, the much vaunted culture of philanthropy in the USA has been fostered by an entrepreneurial and pro-active approach to plugging the funding gaps in the health research pipeline, as illustrated for instance by the towering input of single wealthy individuals and by the venture philanthropy move. There is willingness for personal investment through initiative and/or money, with greater acceptance of risk toward the national pursuit of being the global technology leader.

The UK situation is quite different, less philanthropy on an entrepreneurial level but with a more coordinated, structured approach to encourage philanthropy across all community sectors. Focussed umbrella groups championing health and medical research have been successful in reducing fragmentation and getting like-minded charities to work together toward their common goal.

Singapore is characterised by a relatively 'young' philanthropy culture, such that the Government has realised the value of playing to its strength by focussing on innovation to drive economic competitiveness while externalising responsibility for implementation.

Religion is a major factor that differentiates Israel's nonprofit sector. The link between religion and state and the aspect of Diaspora giving whereby Jews from all over the world contribute to Israeli causes make Israel a unique environment. Judaism has also fostered voluntarism and charity as part of its ethos.

In Canada, Government leadership has targeted leveraging non-government (philanthropy and industry) support to an impressive \$3 from non-government sources for every \$1 invested directly in HMR by the Government.

Australian giving trends and data suggest that while HMR is greatly valued and a common area for personal donation this does not translate proportionately in dollar terms. Some recent innovative partnering across sectors involving government, nonprofit and industry suggest a willingness and new wave of collaboration and joint funding which would be a great boost to HMR philanthropy. Corporate social responsibility programs and corporate foundations seem to be less involved in HMR and anecdotally see HMR as a complex philanthropic cause requiring expertise in selection, a government responsibility, too long term and not offering volunteering opportunities. Some notable exceptions apply.

## 2. International Models of Philanthropy

### 2.1 United States of America

#### Giving overview

Community funding and a spirit of volunteerism are US hallmarks. The US has more than 1.4 million charities and individuals in 2004 donated US\$188b contributing to overall giving of US\$249b (AAFRC Trust 2005). Donations flow regularly from 70% of households and charitable giving in 2004 was estimated at 1.6% of GDP. Most giving comes from individuals (76.3%), then foundations (11.2%), bequests (7.5%) and then companies (5.1%) (AAFRC Trust 2003). It is suggested as a long-term rule of thumb that 10% of Americans do not give. Longitudinal philanthropy studies (eg. Independent Sector, Giving USA) suggest these proportions have remained roughly the same for up to four decades. Much philanthropy is expected from a vaunted intergenerational wealth transfer through bequests.

Some writers (eg. Scheff 2001) seeking to explain the strength of philanthropy in the US culture compared with others attribute this spirit to the country's genesis, moving away as it did from British Government control to an independent nation run 'by the people'. Others suggest US philanthropy has more to do with tax incentives (eg. Grey 1999, who cites the experience of Ronald Reagan withdrawing tax breaks for visual arts donations in mid 80s and their donations subsequently dropping by 70%). Both the US and Australia introduced tax laws related to giving at death in 1915 and these still apply in the US, though are now under review. A complex series of means by which the wealthy can structure their giving for major tax advantage exist including the common use of annuities and charitable remainder trusts (eg. where assets are given during the donor's lifetime and the donor uses the assets needed till their death when they pass to the charity). Financial and other advisers are common in the US, often actively promoting philanthropy as an option in planning the affairs of wealthy clients (The Philanthropic Initiative 2000).

Indeed as Petre says in Moran (2005) there is a stigma in the US if wealthy families do not give. Perhaps this is one reason why the landscape is peppered with major foundation players armed with huge endowments (eg. the Howard Hughes Medical Institute - HHMI). Philanthropy is a major industry in the US. Academic centres investigating the phenomenon are plentiful (eg. Indiana University Center on Philanthropy, Centre for Civil Society, the Aspen Institute). Charity watchdogs are present and vocal (eg. Guidestar, American Institute of Philanthropy, the National Committee for Responsive Philanthropy). Peak bodies serve the sector's needs in general and more highly specialised ways (eg. the American Association of Fundraising Professionals, the Association of Healthcare Philanthropy, the Foundation Center, Grantmakers in Health). Australian peak counterparts have various degrees of contact and exchange with these US groups. A particular impetus from RA could see greater exchange on HMR philanthropy.

HMR peak bodies include Research! America and the American Academy for the Advancement of Science (AAAS). Some philanthropic foundations also undertake the type of advocacy and research often associated with such peaks (eg. the Mary Lasker Foundation and its Funding First project, the Robert Wood Johnson Foundation and its efforts in preventative healthcare).

The US has also seeded some landmark international giving to health and other causes from the so-called 'mega rich'. For instance, Bill Gates has given away US\$28 billion - 37% of his wealth and Intel founder Gordon Moore some two-thirds of his worth equating to donations of US\$8.8 billion) (Moran 2005).

#### Statistical and other information on medical research funding

The three key players in US medical research funding are government, industry and philanthropy, with industry providing most input currently in dollar terms. Sometimes the three sources work in partnership. Their relative funding rankings have varied through the decades. Government's funding share (which comes through the annual appropriations process given largely to the National Institutes of Health) has shrunk from approximately two thirds in 1980 to less than half today (Field, Plager, Baranowski, Healy and Longacre 2002). Health related research has in most years seen federal funding growth since the 1960s as has R & D investment by research-based pharmaceutical companies (Meyers 1999). The lead funding role moving to industry reflects the establishment of thousands of new companies to realise big profits from the advances in microbiology, genetics and computer modelling. These advances have allowed commercial interests to more accurately choose possible compounds to test. Hood (1996) cites Scientific American's comment that 'the biotechnology boom ...transformed a good deal more than the techniques used in the laboratories. It also changed fundamentally the financial environment and the culture of biological research'. Industry supplies some 70% of all funding for clinical drug trials (Staropoli 2003).

In the earlier half of the 20th century when Government was not a large market player, philanthropy played the central role. Two notable examples are the 1910 Carnegie Foundation funding for a study on the state of medical education that saw a complete revamping of the system, and the Rockefeller Foundation's role in establishing the first clinical research hospital, school of public health and the Population Council (Field et al 2002).

These writers chart that The Ransdell Act of 1930 created the National Institutes of Health (NIH) after government efforts failed to promote private-sector research funding in the years after World War I. After World War II, government and private initiatives grew exponentially but independently. Another visible funding agency is the Agency for Healthcare Research and Quality. At the beginning of this century these two major federal agencies spent more than US\$20 billion, and pharmaceutical companies more than US\$30 billion for research. In 2001, nonprofit private foundations contributed approximately \$1 billion to health-related research (Field et al). The different roles filled by these funding sources are described as having resulted through 'historic accident rather than explicit policy design' (Field et al).

## 2.1.1 American Association for the Advancement of Science (AAAS)

<b>Workshop:</b>	How to Fund Science: The Future of Medical Research
<b>Who:</b>	The American Association for the Advancement of Science (AAAS) and the Funding First Program of the Mary Woodward Lasker Trust
<b>Where:</b>	Maryland
<b>When:</b>	14-16 Feb. 1999
<b>Why:</b>	To examine fresh ideas and perspectives
<b>What:</b>	The Funding First Program is an initiative of the Mary Woodward Lasker Charitable Trust designed to build 'the case for a sustained, long-term national commitment to medical research with key decision makers and the policy community, and publicizing the case with high profile leaders in public and private sectors' ( <a href="http://www.laskerfoundation.org">www.laskerfoundation.org</a> ). The AAAS is similar to the Australian counterpart.

Some thirty budget process experts, public policymakers and scientific research leaders met to discuss alternative funding mechanisms for medical research outside the volatile appropriations process. Key workshop discussions included:

- Advancing Funding First's thinking on taking medical research funding beyond the annual appropriations process to a more stable basis through:
  - Setting up a trust fund for medical research with revenues derived from a specified amount of general revenue, taxes on private health insurance premia and taxes and/or royalties on sales from medical products (eg. Giving manufacturers of proprietary pharmaceuticals up to ten years of additional market exclusivity/patent extension for certain products with royalty payments made to Government). (For full detail see Meyers 1999). The workshop concluded the appropriations system needed to stay but could be complemented by this type of trust fund with a dedicated funding source such as taxes on tobacco product sales or those canvassed above. An additional thought of Federal reallocation of funds within the Highway Trust Fund to support research in transportation-related injuries was also suggested.
- Mandating that public and private insurance systems pay the cost of health care services for beneficiaries participating in federally supported clinical trials, except those linked to a patentable product or commercial profit. This is on the principle that those benefiting from the improved public health coming from such trials should share the cost of them.
- The Research and Experimentation (R&E) tax credit should be made permanent and expanded to include research in clinical trials.

**More information:** [www.aaas.org](http://www.aaas.org)

## 2.1.2 The University of the Sciences in Philadelphia symposium on medical research funding

<b>Workshop:</b>	Symposium to discuss medical research funding issues.
<b>Who:</b>	University of the Sciences in Philadelphia, representatives from government, industry and foundations (funded by the Eli Lilly and Company Foundation).
<b>Where:</b>	Philadelphia.
<b>When:</b>	September 2002.
<b>Why:</b>	'The financial support for America's medical research enterprise has three primary but distinct sources: government, industry and foundations. For the most part, they function in separate spheres, with little coordination. The result is gaps that leave some research needs unmet and opportunities for collaboration overlooked. Moreover, emerging areas of inquiry that cross the traditional roles of funding sources, such as biodefense and genetic technologies, may challenge the ability of the existing structure to respond.' (Field et al 2003).
<b>What:</b>	The workshop explored three primary concerns with funding infrastructure: constraints on research, areas in need of further research and the need for new funding approaches. Issues such as lack of qualified investigators, decrease in physician-scientists, onerous accountability to funding sources and difficulty of publication of studies that report no effect were canvassed. The possibility of greater use of insurance as a new funding source arose relating to clinical studies. State funding particularly through tobacco company legal settlements was discussed.
<b>More information:</b>	Towards a policy agenda on medical research funding: Results of a symposium, Robert I Field, Barbara J Plager, Rebecca A Baranowski, Mary Anne Healy, Margaret L Longacre. Health Affairs Chevy Chase:May/June 2003. Vol. 22, Iss. 3, p. 224-230

### Ideas takeout:

- The workshops themselves as a multi-stakeholder roundtable.
- The feasibility of the funding ideas raised could be further considered (insurance, tobacco taxes, a national trust fund with a dedicated income stream).

## 2.1.3 Venture Philanthropy (VP)

An increasingly popular and sometimes controversial form of philanthropy evident as a niche in the US (and elsewhere) is venture philanthropy. While it operates under several models, in essence, VP seeks to apply the principles of venture capitalism to social organisations and needs. A typical example might be a group of young technology tycoons donating cash and stock options to create a fund to help unemployed youth start an internet business. The business in turn creates employment and becomes self sustaining with the funding and business advice of the entrepreneurs who help develop its revenue streams. Unlike a one-off grant, VP usually is an ongoing dialogue over some years and the return sought is social improvement rather than dollars. Thus, if applied to medical research discoveries, VP investor/donors would not necessarily look to reap intellectual property (IP) benefits for themselves.

This form of philanthropy has become popular in the 'new-economy' hotspots such as Silicon Valley. Entrepreneurs are said to differ from traditional donors, seeking broad impact, the ability to measure that impact and a wish to not only share their wealth but the strategies behind it. Some commentators (eg. Billiteri 2000b) see VP as an 'antidote to ... the failings of mainstream philanthropy'. These shortcomings are seen as a lack of support for innovation and infrastructure among charitable organisations, with most funding short term and project driven. A further lament is lack of dissemination of successful programs for replication. Charities are seen by venture philanthropists as 'chronically undercapitalised'. As Community Wealth Ventures (2002) suggests

Current methods of funding and supporting non-profits can be improved. Non-profit organisations exist in a culture of dysfunction - limited capacity and modest outcomes pervade critical organisational elements such as strategic planning, staffing, training, management, financing and performance measurement.

This report concludes nonprofits are unable to capitalise for future growth. Early stage biotechnology entities might warrant a similar comment, if transferring this concept to HMR.

The report describes nonprofits as compassionate and committed service providers but inattentive institution builders. Money invested in organisations is considered lost to direct services. A climate of media and donor scrutiny of fundraising and administration cost ratios intensifies this lack of investment in the organisation which is after all 'the goose that lays the golden eggs'.

Some prominent US foundations have gone part way along the VP road. For example, the James Irvine Foundation in San Francisco has started a \$6M innovation fund that can form partnerships with non-profits and businesses.

Most VP cases cited involve causes other than HMR. However, two examples of this thinking applied to HMR have been located and are canvassed as case studies US4 and US5. Another example of VP is cited in the Israeli section, although it is not specifically targeted to medical research.

**More information:** [www.sbtcd.org/technology/philanthropy.htm](http://www.sbtcd.org/technology/philanthropy.htm)

### Ideas takeout:

- Entrepreneurs from new industries are a potential donor and 'energy' pool, given the right incentives and opportunities for hands-on involvement (In Canada whole strategies have been built to attract this group to philanthropy while in the US, the new technology sector with its crop of fresh millionaire and billionaires has for some years been viewed as a fertile source for new philanthropy);
- Traditional foundations may be open to funding innovation and collaboration (such as the type described in the next case) as a sideline activity to their more traditional grants - 'toe in the water' venture philanthropy rather than changing their total modus operandi;
- Building nonprofit capacity and investing in the quality of the institution are desirable if the outcomes from the sector are to improve.

## 2.1.4 Goldman Philanthropic Partnerships (GPP)

(formerly the Judith and George Goldman Foundation Fighting Catastrophic Diseases)

**Who:** Merchant bank founder, chairman and entrepreneur George N. Goldman (Chair), Judith A. Goldman (Vice-Chair), Dr Bruce Bloom (CEO)

**Where:** Illinois based, funding across USA research institutions

**When:** Founded 1998

**Why:** Judith Goldman was diagnosed with Multiple Myeloma in 1990 and benefited from non-traditional techniques. The pair became committed to what they call 'philanthropic activism'

**What:** Organisation set up to 'change and accelerate the way cures are discovered, creating innovative research funding partnerships between donors, researchers and medical institutions'. These partnerships called Inspired Ventures are based on the business model of a limited partnership or venture capital investment and use both business and fundraising practice. Tools used to achieve these partnerships are:

- Each donor selects from a portfolio of projects sought from well known HMR institutes (eg. Stanford, Harvard, Mayo, Sloan Kettering) and gives to a specific research project in their area of interest (to maximise the funding and donor participation) rather than generally giving to an organisation or institution;
- GPP allays donor fears about the donation reaching the mission end of the business by overseeing the project budgets and ensuring no extraneous expenses are incurred;
- For every charitable donation, GPP secures a matching donation of at least dollar for dollar from the research institution itself or another organisation;
- Each project is validated by the nominating institute and GPP's science advisers;
- Progress is reported to donors every 90 days.

**Other elements:**

- Focus is on breakthrough research and funding collaborations to achieve it
- Each research project has a business plan with specific goals to be evaluated every 90 days
- GPP presents Angel Awards for outstanding achievement (groundbreaking scientists, patient advocates, journalists, statesmen and politicians or individuals)

**In summary:**

- Major donors are given an easy path to funding something that has been validated, is going to be managed in a businesslike way, with opportunity for personal involvement and regular accountability and updates. Their funding leverages at least a doubling of their financial input.
- Researchers are encouraged to muster novel ideas and helped to achieve funding and collaborations.
- HMR institutes double their input to cutting-edge research that is unlikely to attract mainstream funding, foster a culture of greater innovation from staff, and gain access to new major donors.

**More information:** <http://www.goldmanpartnerships.org>

**Ideas takeout:**

- Potentially a feasibility study opportunity for a philanthropically inclined venture capitalist or for an innovative foundation here.

## 2.1.5 Institute for the Study of Aging

**Who:** A biomedical venture philanthropy, endowed by the Estee Lauder Trust that started as a private charity to locate a cure for Alzheimer's disease. With a limited budget of some millions to disburse each year, family members sought the best way to leverage that money so it could do most toward the mission. Hence they coined the phrase 'biomedical venture philanthropy' and created a model that could target the money to the areas where funding was scarce (discovery and validation) and involve other funders in the process. 'We had only limited money in the scheme of what was needed and wanted to work out how to do most with the money we had to donate to this aim. We wanted to be innovative with the funding as much as with the drug discovery' (ISOA CEO Dr Howard Fillit).

**Where:** New York

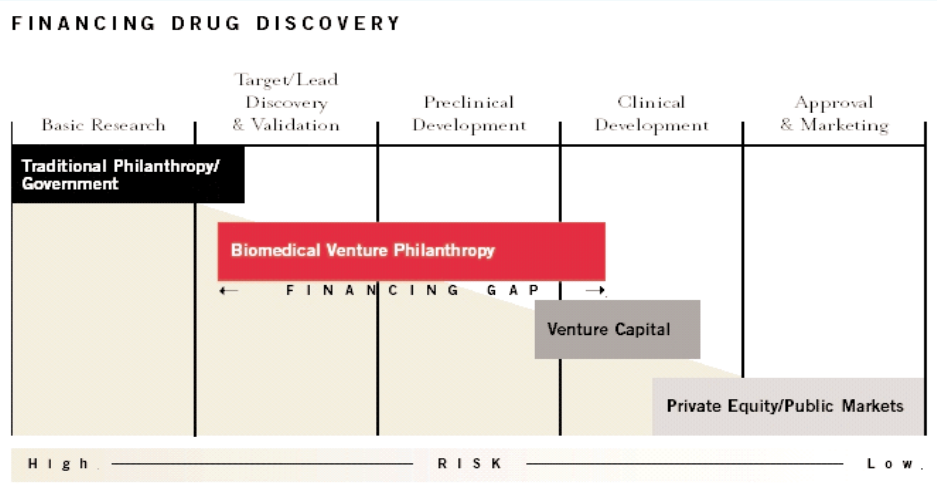
**When:** 1998

**Why:** 'To catalyze and fund the discovery and development of new therapies to prevent and treat Alzheimer's disease'. 'Academic and biotechnology companies are playing an increasingly important role in the early stages of Alzheimer's disease drug discovery and development. However, academic scientists with innovative ideas for new drugs have difficulty finding support for their work, and early stage biotechnology companies have difficulty raising capital because drug discovery is viewed as a high risk investment.'

ISOA fills the gap between traditional funding of basic research by government and clinical development funded by later stage investors (eg. venture capitalists and pharmaceutical companies).

**What:** 'ISOA has adopted this model to fund drug discovery research and development for Alzheimer's disease. Operating like a venture capital firm, ISOA identifies innovations in academia and in industry with high potential in the area of Alzheimer's drug discovery and development, supports these innovations with financial, technical and strategic management assistance, establishes networks and collaborations, and monitors outcomes.'

As a biomedical venture philanthropy focused on drug discovery for cognitive aging and Alzheimer's disease, ISOA bridges the funding gap between basic science research and pharmaceutical drug development. By providing funding to advance early stage technology, ISOA funding can lead to further investments by other investors such as venture capitalists, investment banking and pharmaceutical companies.'



([www.aging-institute.org/venture.htm](http://www.aging-institute.org/venture.htm))

Since 1998, more than US\$23M has been committed to support 132 research projects and conferences at key academic institutions and biotechnology companies in 9 countries. Some of its collaborative funding also goes toward investigating the impact of clinical and economic issues related to cognitive aging and particularly the processes and outcomes of geriatric care. ISOA funds start-up and early-stage biotechnology companies using either program investments or recoverable grants. It runs a Biotechnology Founder's Program. Philanthropists have established awards for scientists excellent in drug discovery that are given to the scientist's institution for further research. ISOA has also teamed with the Alzheimer's Association and Pfizer Inc. to establish the Alzheimer's Research Consortium to support development of new animal models.

**Comment precis from CEO Dr Howard Fillit**

Family foundation motivation for this non-traditional giving.

"The family had funded medical research over a long time. We reached a point where the family and I wanted to be more effective than the usual cheque writing often allowed you to be. We view philanthropy as a business - a nonprofit business. This area of biomedical venture philanthropy is still an emerging, evolving field."

**Getting started.** The first step was recognising the mission - funding drug discovery at the pre-clinical stage, where government seldom funds and traditionally it is left to pharmaceutical and biotech companies. Funding here is not large because pharmaceutical companies do what is good for their business naturally, which means avoiding higher risk and likewise biotech companies find it hard to interest investors in risky early stage discovery. Philanthropists and government fund at the basic level but we believe one of the things philanthropy exists to do is to take some of the risks that other funders find it harder to do. It took legal and contracting strategies then to make grants possible to both the academic and biotech organisations. To date approximately 80% of our funding has been channelled to academic research in this area and 20% into biotech firms. We formed a public charity eight months ago to help with further fundraising and funds and supplement what the private family foundation was able to do. We have ISOA Inc - our private foundation and ISOA Ltd - a public charity.

**Working with donors.** Donors make donations to us as a charitable exercise. We can and do structure contracts to seek return on investment but it is a modest return (eg. a percentage of net sales on any licences, scientific or business milestones in the case of biotech companies). Any returns would come back to ISOA for further charitable investment in the mission, not to the individuals as this would be violating our charity laws. Notionally if a foundation gave us money theoretically it could go back to the donor foundation for further investment in the cause, I suppose. The hard bit has been generating the further dollars and convincing people that this departure from tradition is a good thing to do. It has meant changing the way people think about giving and how they think about what academic research centres can do. It has meant educating people that these centres can do drug research and it is not just something to be left to pharmaceutical companies alone.

**Entrepreneurial emphasis.** These donors tend to be more entrepreneurial. In the eight months we have operated the public charity we have found people like the model for that reason - it is entrepreneurial. Part of our model is we have made our organisation like a venture capital firm rather than a traditional charity. We have four full time staff and an emphasis on technical expertise so our organisation can play an active role in vetting the science. We emphasise being leaders in the technical field and in bringing experience in research and venture capital.

**Relationship with biotech players.** We have established two start-up biotech companies as founding investors. We played a nonfinancial partnership role in taking these to venture capital stage, giving the imprimatur - the legitimacy. The science had been validated because we did the due diligence. So when the venture capitalists came in they knew this was something that had been vetted. We talk to the venture capital firms but do not have a financial relationship with them.

**Relationship with charities.** We partner a lot with charities, doing co-funding.

**Relationship with research institutions.** We fund all over the world and don't focus on one or several particular institutions. We seek applications and where we see interesting technology we might proactively seek out that organisation. Our website is well used and our reputation has grown over time.

**Relationship with government.** We just did an NIH partnering program. The National Institute of Aging has a \$1.5B budget and we have been able to advocate for stronger funding for Alzheimers.

**Relationship with pharmaceutical companies.** We receive funding from and fundraise with pharmaceutical companies (donations from their corporate citizenship activities).

**Other models.** Several other disease specific areas have followed a similar model, including the Junior Diabetes Research Foundation and cystic fibrosis.

**More information:** [www.aging-institute.org/venture.htm](http://www.aging-institute.org/venture.htm)

#### Ideas takeout:

- Linkages with a philanthropic trust for the endowment.
- Emphasis on the business approach and entrepreneurial giving.
- Staffing by specialist technical people.
- Collaborative funding with philanthropists, the donating public and the corporate donations side of pharmaceutical companies to boost funding for the early risk stage of drug discovery.
- Active input to founding biotech firms, including recoverable grants (so the start-up well doesn't run dry).
- Structuring a modest potential return on investment.
- Advocacy and education role with government and the giving community.
- Venture philanthropy model tailored for medical research.

## 2.1.6 Corporate giving and partnerships

Who:	Summary by Townsend
Where:	Texas
When:	2002
Why:	'provides the extra measure of excellence and extra dollars ... and a safety net for academic researchers'
What:	Fierce competition for NIH grants sees one in three proposals granted and few going to young scientists without a track record. Corporate donations allow universities to build cutting edge facilities and purchase latest equipment. Examples include multi-million dollar donations for research equipment and public health programs by Exxon Mobil Corp and Kimberley-Clark's large support of neurological research. Donations also flow for gifts related to the corporate's field (eg. Pearl Vision's donation to UT Southwestern for contact lens research). Corporations also commonly support scientific research heavily through event sponsorship and donations to nonprofit health agencies (eg. the Eye Ball supporting ophthalmology research).

**More information:** Townsend (1999).

### Ideas takeout:

- Research Australia could investigate local offices of companies giving to medical research overseas to encourage giving in Australia. Part of this process may be a volunteer/consultant prospect researcher identifying international companies that fund medical research that have an Australian arm.
- Research Australia could showcase for HMR charities the elements of such partnerships with cooperation from companies giving to HMR (similar to the ABAF Gold and Red Books, the ABAF awards etc).
- Research Australia could version and expand a report for corporate foundation executives and convene a roundtable of these executives to seek their input on ways to improve the suitability of HMR for corporate partnerships or philanthropic funding (information on a similar exercise undertaken in Canada to help spark funding for nonelite sport is available through a previous CPNS study).

## 2.1.7 Howard Hughes Medical Institute

Who:	Entrepreneur, the late Howard Hughes
Where:	Chevy Chase, Maryland, funding worldwide
When:	Founded 1953
Why:	Purportedly to deprive the IRS of his wealth.
What:	Largest source of private funding support for biomedical research and science education. Endowment in 2004 was US\$12.8 billion. More than US\$1.5 billion in grants have been given out to enhance science education since 1988. Hundreds of millions of dollars each year are invested to support basic medical research, science education programs to train the next generation, and to increase the scientific literacy of the public across USA research institutions.  Also is an operating medical research institute so funding is applied to Hughes-funded investigators, consonant with Hughes' philosophy of not giving research grants but rather funding 'people not projects'.

**More information:** <http://www.hhmi.org>, McKivergan (1999).

### Ideas takeout:

- A basic major giving tenet is that it takes large ideas and visions to excite people to give large gifts. The Wellcome and Howard Hughes style examples and their sheer impact offers this kind of model.
- Specialist prospect researchers operate internationally to identify people with large capacity to give and potential linkage to a cause. Research Australia could initiate and fund such a search.

## 2.1.8 Grantmakers in Health

<b>Who:</b>	Peak body for Health Grantmakers
<b>Where:</b>	Washington DC
<b>When:</b>	1982
<b>Why:</b>	To help foundations and corporate givers improve the nation's health
<b>What:</b>	A nonprofit, educational organization fostering 'communication and collaboration among grantmakers and others, and to help strengthen the grantmaking community's knowledge, skills, and effectiveness...

GIH generates and disseminates information about health issues and grantmaking strategies that work in health by offering issue-focused forums, workshops, and large annual meetings; publications; continuing education and training; technical assistance; consultation on programmatic and operational issues; and by conducting studies of health philanthropy. Additionally, the organization brokers professional relationships and connects health grantmakers with each other as well as with grantmakers in other fields whose work has important implications for health. It also develops targeted programs and activities, and provides customized services on request to individual funders'. (<http://www.gih.org>)

A sample recent publication is: Building Relationships in Health: How Philanthropy and Government Can Work Together.

**More information:** <http://www.gih.org>

## 2.2 United Kingdom

### Giving overview

UK philanthropy has just been through a major injection of research and promotion in the form of the three year Giving Campaign. The £1.3 million Campaign funded mostly by Government, set up a partnership with the major philanthropic peaks to make most impact in its three year life (including Charities Aid Foundation, the National Council for Voluntary Organisations, the Legacy Promotion Campaign, the Association of Charitable Foundations, Business in the Community, the Community Foundation network, Institute of Fundraising, Charity Commission and others). Reactions on the success of the initiative vary.

In 2000, the Chancellor improved tax incentives for giving, including Share giving, which combines relief on income and capital gains tax and Payroll Giving. Estimates suggest that only 2% of employees and 1% of employers participate in payroll giving, compared to 25% and 35% in the US. In 2001, two-thirds of the adult population donated to charity, mostly not in any planned or tax effective way. As in other international giving studies, the poor were more likely to give a larger percentage of household expenditure than wealthy people (defined as those on higher tax brackets). Also in common with many western nations, the average age of donors is high (approximately 55) and the proportion of under-30s giving is low and slumping further after a twenty-year decline. The campaign targeted the wider population to encourage them toward a 1.5% of income benchmark for giving and think about making a bequest to charity in their will. Only 4% of people did so in 2001. The Campaign also worked with strategic markets. Students in the 11-16 age group were exposed to a new Giving Nation curriculum as part of their citizenship studies. Charities were encouraged to: be more open and transparent with donors, collaborate more, promote tax reliefs actively, train their board members better, engage young people and focus their efforts on major gift fundraising. Because corporate philanthropy is declining in real terms in the UK, corporate leaders and small business owners were exhorted to lead giving as research indicates this example influences employee giving.

Targets such as a 10% participation rate in payroll giving, making matching donations and also looking into tax advantages of corporate donations were major thrusts. Government set about simplifying tax relief and looking at some of the US vehicles such as Charitable Remainder Trusts and other opportunities for more planned giving. Professional advisers were encouraged to include a question about charity in their preliminary client discussions and develop new financial products that made it easy to give. Media through national editors were encouraged to run more stories about modern charity, offer more free space where possible and present role models that make giving as much a part of life portrayed on TV, radio and in the press as it is in reality. At the close of the campaign, some of the targets had been met with improvement across all aspects of giving. The flow-on is a set of strategies spread around the various peaks to double UK charitable giving by 2014 ([www.givingcampaign.org.uk](http://www.givingcampaign.org.uk)). Historically, growth in charitable foundations occurred in the 1930s, 1960s and 1970s, correlating with introduction of tax incentives.

### Statistical and other information on medical research funding

The UK-based pharmaceutical industry funds one-third of the UK's industrial R & D (Stephen Pincock 2004a). Charity funding represents a significant proportion of the total expenditure on UK medical and health research (approx. one third) and is a situation without parallel elsewhere in the world. (Association of Medical Research Charities 2005) As part of a ten year plan to boost science and innovation, the Chancellor last year pledged an R & D budget increase to £1.2 billion a year by 2008 to be used in part to underpin a new Clinical Research Collaboration, embracing the Medical Research Council, the Wellcome Trust, charities, the National Health Service and patients. The details of the framework were defined after a consultation exercise with the research community, charities, industry and universities. Pincock (2004b) also reports that millions of dollars from within and outside the UK have been invested by funding organisations for stem-cell research.

Five AMRC member charities (Arthritis Research Campaign, British Heart Foundation, Cancer Research UK, the Health Foundation and the Wellcome Trust) together spent £578M in 2002/03 and accounted for approximately 87% of the total UK medical and health research funding from AMRC charities. The majority of AMRC member charities spend less than £1m per annum, with many spending less than £100,000 (AMRC 2005). Cancer research accounts for approximately a third of AMRC funding.

AMRC commissioned a study on 'the contribution of AMRC members to UK biomedical research outputs between 1988 to 2000 using bibliometric methods. Biomedical research publications were analysed using the Research Outputs Database (ROD) to determine which publications acknowledged AMRC members as funders of the research. Between 1988 and 2000 over 100,000 publications cited AMRC members' support, compared with a little over 60,000 publications acknowledging the Medical Research Council. During this period there was an overall increase of 31% in the number of papers citing AMRC member funding. Analysis of the institutional origin of the publications revealed that about 76% came from universities and 46% were from hospitals.

A more detailed study of AMRC members' 'contribution to university biomedical research in 32 different areas of research showed that this averaged 30%. That means that of all the papers produced, AMRC members were acknowledged on average on one in three publications. In seven areas of research, motor neurone disease, multiple sclerosis, arthritis, diabetes, cardiology, oncology and stroke, AMRC members were acknowledged on over half of the publications (if papers without citations were excluded)' (<http://www.amrc.org.uk>).

## 2.2.1 UK University Challenge Fund

- Who:** Collaboration between the Office of Science and Technology (originally contributing £25 million), the Wellcome Trust (£18 million) and the Gatsby Charitable Foundation (£2 million).
- Where:** UK
- When:** 1998 first round, 2001 second round, now continued as part of the Higher Education Innovation Scheme.
- Why:** To seed funds that help technology transfer at the risky 'valley of death' stage of university research discoveries into a form where venture capitalists have 'proof of principle' and will take them up (eg. funds to construct prototypes, create a business plan and so on)([www.hefce.ac.uk/reachout/heif](http://www.hefce.ac.uk/reachout/heif)). This scheme differs somewhat from Australia's Higher Education Innovation Program.
- What:** The objectives of University Challenge were to:
- 'Allow winning universities ready access to seed-fund capital to turn the results of research into potential new businesses and/or products;
  - Catalyse the activity in seed funding of high technology, an area still not well served by the UK Venture Capital industry;
  - Educate UK universities in the investment process and bring the financial community closer to universities;
  - Provide stimulus to entrepreneurial activities in the university sector'. ([www.ost.gov.uk/enterprise/unichal.htm](http://www.ost.gov.uk/enterprise/unichal.htm))
  - Fifteen seed funds resulted from the first challenge, involving 37 institutions. Subsequently a new venture capital fund has been set up of funds for investment in UK based early stage technology companies, funded by public/private funds.
- More information:** <http://www.ost.gov.uk/enterprise/unichal.htm>; Ogilive 2000

### Idea takeout:

- This represents a partnership effort from philanthropic and other funding sources to target a particular gap in the nation's HMR strategy.

## 2.2.2 Association of Medical Research Charities (AMRC)

<b>Who:</b>	AMRC is a 112 strong membership organisation of the leading UK charities that fund medical and health research.
<b>Where:</b>	UK
<b>When:</b>	Founded 1972, established as a charity in 1987
<b>Why:</b>	To provide effective support and leadership for its members and the wider charity sector involved in HMR through the provision of information and guidance and a strong and credible representative voice. AMRC responded to a need to raise the credibility of charity funding and to educating the public to the benefit of a diversity of funding sources for HMR (beyond government).
<b>What:</b>	AMRC's main activities are: <ul style="list-style-type: none"><li>• 'To identify and provide information on key issues affecting the sector;</li><li>• To lead in the development of appropriate and sustainable positions and policies for the sector;</li><li>• To represent the concerns, policies and positions of member charities to Government and others, as appropriate;</li><li>• To support medical and health research charities through the dissemination of information on issues of concern, the development of best practice and the provision of advice, support and training;</li><li>• To promote public awareness, recognition and support for the contribution of UK based medical and health research charities through work with key audiences and the media;</li><li>• To ensure that the research community is able to access accurate information and guidance on the funding opportunities available from member organisations'. (<a href="http://www.amrc.org.uk">http://www.amrc.org.uk</a>)</li></ul>

Most member charities have outreach to the many stakeholders in their interest area including: 'clinicians, nurses and other allied health professions, laboratory-based scientists, computer experts, complementary therapists, carers and health service researchers and so on, as well as patients themselves'. CEO Diana Garnham reports this access to patients connected with these organizations to encourage them to participate in clinical trials is another benefit the organization brings. While they provide usually smaller 'pots' of research funding, it is seen as more flexible than other sources. Garnham describes HMR charity funding as part of a long tradition and cites the relative ease of setting up a charity in the UK as one factor in this. AMRC tries to foster a culture in charities and in government that good charitable funding linked with government input is about creative health partnerships.

'Members must show that undertaking medical and health research in the UK is a principle activity (usually defined in their objects), that they are registered with the Charity Commission in England and Wales, or otherwise recognised as a charity in Scotland and Northern Ireland, and they meet AMRC's criteria for a well run medical and health research charity.

AMRC's membership criteria require that charities use a method of peer review that meets AMRC's guidelines for the allocation of grants and awards for research. These criteria ...will be extended in October 2005 to include the requirement to have a published research strategy. An important part of AMRC's role is to develop guidance on peer review and other issues that affect the way in which medical and health research is supported. Other areas of guidance include the legal duties of trustees, management of intellectual property, use of animal experiments and patenting of human genetic information.'

...'Even if their financial contribution might be relatively small, the support a charity gives to medical and health research helps to maintain the interest of the scientific community in the disease, so that areas of research are never quite fully abandoned. Many charities which support research also work in the field of patient support and in education. Those charities which focus on a single disease often have a very close association with sufferers and this helps to inform the charities' priorities.'

...'As charities, their purpose in funding the research must be for public benefit and not for commercial or private gain. Because charities are established with a particular stated objective or purpose they are not free to redirect their support to other areas, even when these may be seen by some as having a higher priority. One advantage of this restriction is that charities maintain their focus over the long-term and are not distracted by changing policy demands or the latest 'hot topic'. This consistency offers a welcome sense of stability and continuity to researchers, at least for part of the funding within each scientific area. It also means that over time, the charity is likely to be one of the organisations with a clear understanding of the state of research in a field and be able to identify opportunities should funding become available.

...Charities believe the university environment is generally a good place to conduct research and they see this type of arrangement as a partnership with the university or NHS Trust enabling both to pursue the best and most timely research questions. Because this is a partnership, AMRC charities expect universities and NHS trusts to provide the underpinning funding for any indirect costs or patient care costs associated with conducting the research.

...There are broadly three types of support: responsive mode funding, where individual researchers apply for time-limited funding such as project grants or fellowships; infrastructure funding where charities support longer term initiatives involving larger research teams or departments which may involve supporting a unit, refurbishing laboratories or providing new facilities and buildings and research supported in charities own institutes. Charities are increasingly supporting longer-term programmes of research in partnership with host universities and other funders.

The breadth of methods of funding is increasing as charities respond to changing environments and the needs of their particular research areas. For example, analysis of AMRC data showed that in 1991 project grants accounted for approximately 60% of research funds, while in 2000 only 30% of awards were in the form of project grants, with increases in programme grants, unit funding and personal forms of support.

Current issues of focus reported by AMRC include making research a frontline service in healthcare, with the entire health delivery community understanding the importance of research. Currently it represents less than 1% of health service budget. AMRC sees groups such as the unions as allies in this process, working with them to encourage their focus to be not just about money but more about the environment. AMRC is concerned about the knowledge not translated to improvements in healthcare - the backlog of ideas still to go into clinical settings and has identified key obstacles as funding and culture. AMRC is not strongly interested in tax incentives for HMR philanthropy, seeing tax incentives as a divisive issue in the charity sector. Another advocacy front for AMRC is inspiring young people to be pro-medical research, in an environment where young people tend to linking to non-health causes, creating a funding deficit potentially some decades ahead.

The UK voluntary sector is seen as leading in terms of openness and care of decisions and HMR charities are seen as possibly ahead of the wider sector in this role. HMR charities are said to do well in a competitive charity environment, with 80% of the community giving to medical research and the field garnering approximately 15% - 18% of charitable giving not including endowments. Awareness raising on the transparency issue is an important role AMRC fills. Random charities offering very small amounts of local money are seen to challenge the quality of overall HMR spending and the organisation encourages such groups to spend in partnership with a national HMR charity to gain the benefits of a research plan, research manager and so on.

Less focus is seen by charities on the very large individual contributions, compared with the US. Garnham reports very rich people in the UK tend to be the exception and generally medical research is not a frontline cause for them. While there is no Bill Gates, some wealthy people have set up foundations to focus on individual disease streams (eg. Edmond Saffra and Parkinsons disease, JK Rowling in MS research due to mother's death from this.). Invariably enquiries to AMRC are about the individual disease areas and Garnham suggests this is an inhibiting factor. She would like to see charitable foundations forged around wider science (eg. cell biology) but people do not set up foundations for such concepts. Medical research is not a major destination of philanthropic foundation funds which Garnham reports are tending to flow more toward the arts currently. Few AMRC members receive large corporate funding, which tends to go to areas where a greater synergy of interest can be identified. Garnham sees technology companies across the spectrum as one potential partner area, finding people like Bill Gates who already are alert to the benefits of new technology.

Reasons for not giving to medical science include the inability to see the outcome, the funding being too longterm, it cuts up animals, it is secretive, too much money is already going in, it's a government responsibility, we know enough already, we don't need more medicines. AMRC counters some misconceptions by running debates in different settings (eg. Workman's Institutes, schools, science festivals).

**More information:** <http://www.amrc.org.uk>

#### Idea takeout:

- AMRC is a ready-made model for improving the calibre, unity, collaboration and impact of Australia's HMR charities. It already reports an international focus and is in discussions with Canadian and European colleagues to measure how philanthropy value adds to HMR.

## 2.3 Singapore

### Giving overview

The charity sector in Singapore is described as 'fairly healthy' (Ministry of Community Development, Youth and Sports). With a government philosophy that 'does not believe in the welfare state' (Chua 1999, p.2) individuals and community organisations are much encouraged to meet a wide range of needs. An important stakeholder not noted as much elsewhere is the clan association. Religious groups are also active in the sector. Philanthropy itself has been an area promoted by Government in recent years. The Ministry of Community Development, Youth and Sports (MCDS) and the National Volunteer Centre (NVC) sought public feedback in 2003 for ideas to build the infrastructure of giving. (Australia's Prime Minister's Community Business Partnership ran a similar exercise in 2004). Ideas ranged from a public education program on giving to rebates/benefits to companies when a certain percentage of their staff volunteer, and on to a national register of needs/projects and charities fulfilling them.

Similarly to Philanthropy Australia, NVC now acts as a 'first stop centre to advise philanthropists' on social investment and report more donors seeking 'enterprising, outcome driven programs' and more direct involvement with funded projects so they can transfer corporate skills. Evaluation criteria for helping donors assess where to place their funding is provided by NVC along with input to nonprofit organisations to build their accountability and ability to build donor relationships. NVC is considering the feasibility of allowing prospective recipients of donations to post their needs on-line. The National Kidney Foundation (NKFS) profiled below is the largest charitable organisation in Singapore. It is rare to see a medical research organisation as the largest charity with this role often filled by an international aid agency or social welfare group. Partnerships are being actively promoted by the Singaporean government with the Health Minister releasing recently a 'many helping hands' strategy. Little academic research was uncovered about philanthropy in Singapore. One study identified strong links between educational attainment and giving as well as between increased tax incentives and private donations (Chua 1999).

### Statistical and other information on medical research funding

HMR giving in Singapore has been influenced to some degree by HMR being placed as a higher priority for economic competitiveness. More on the push toward a 'vibrant Knowledge-Based Singapore' ([www.a-star.edu.sg](http://www.a-star.edu.sg)) is included in the Philanthropic/HMR programs of note section. With an aging population and sharp decline in fertility (Chua 1999, p.4) the demand for health philanthropy is increasing. In 2003, the SingHealth Foundation was formed by the healthcare service that operates nine of Singapore's public hospitals/health centres to create an endowment for HMR.

## 2.3.1 Agency for Science, Technology and Research (A\*STAR)

- Who:** Singapore's National Medical Research Council was set up in 1994 and works similarly to the Australian model. More latterly it has been complemented by an education based agency that builds the science base more cross-sectorally - A\*STAR.
- Where:** Singapore
- Why:** 'Knowledge creation and exploitation of scientific discoveries for a better world' ([www.a-star.edu.sg/astar/about/action/keyfocus.do](http://www.a-star.edu.sg/astar/about/action/keyfocus.do))
- What:** Fosters world-class scientific research and nurtures scientific talent by charting the course for Singapore's Science and Technology. Comprises the Biomedical Research Council (BMRC), the Science and Engineering Research Council (SERC), Exploit Technologies Pte Ltd (ETPL), the A\*STAR Graduate Academy (A\*GA) and the Corporate Planning and Administration Division (CPAD). The two councils 'promote, support and oversee the public sector R&D ...and ... fund the public research institutes'. Four R&D capabilities strengthen key industries in Singapore (Pharmaceuticals, Biotechnology, Medical Devices and Healthcare Services clusters). Specific focus areas exist with the BMRC. For instance, the Singapore Cancer Syndicate 'funds cancer research infrastructure and consortia'. Its aim is to 'achieve a coordinated and advanced clinical discovery and validation infrastructure within the shortest period of time'. Funding is channelled to academic groups but alliances with industry are fostered. 'The Singapore Cancer Syndicate is a new approach to scientific funding, which...will excite our scientific community and propel Singapore as a key center for clinical-translational research.'

**More information:** <http://www.a-star.edu.sg>

### Idea takeout:

- Economic benefit effectively used as driver for placing medical research higher on agenda and achieving more government funding and cooperation;
- Role that the education sector has played in forging the industry linkages that will underpin better medical research outcomes;
- Single disease funding and activity syndicates.

## 2.3.2 SingHealth Foundation

- Who:** SingHealth was set up by the healthcare service that operates nine of Singapore's public hospitals/health centres to create an endowment for HMR..
- Where:** Singapore
- When:** Founded approx. 2003
- Why:** 'To fund research, education and healthcare for the needy
- What:** Has established a major gifts and general fundraising program to put in place resources in its centres of operation such as a Cord Blood Bank and an endowment for research (the Cure program).

**More information:** <http://www.singhealth.com.sg>

### Idea takeout:

- Model for amalgamated HMR fundraising for predetermined multi-disease projects across a number of sites.

## 2.3.3 National Kidney Foundation Singapore

<b>Who:</b>	Singapore's largest charitable organisation and single largest not-for-profit dialysis provider in the world. It calls itself 'The Corporate Charity' because it is run on the latest corporate strategies.
<b>Where:</b>	Singapore - also formed the World Kidney Foundation 'to help provide renal communities in underdeveloped countries with the expertise to create self-sustaining non-profit organisations through training and outreach programmes.'
<b>When:</b>	Founded 1969 - tagline is 'Leading social entrepreneurship in Singapore for 35 years'.
<b>Why:</b>	Singapore has the third highest incidence of kidney failure in the world and very high prevalence of hypertension and diabetes, leading causes of kidney failure. Established the world's first public-funded subsidised dialysis programme in 1987 because patients faced inevitable death or bankruptcy because of expensive dialysis treatment.
<b>What:</b>	Preventive healthcare and patient care; <ul style="list-style-type: none"><li>• Public and nursing education;</li><li>• Medical research;</li><li>• Fundraising and communication activities (including major business partnerships and Corporate giving programs like Lifedrops where companies donate through a monthly donation scheme along with the more common Give as You Earn programs for employees);</li><li>• Advocates for legal change (eg. making it possible for organ donors' wishes to be sacrosanct);</li><li>• Built the 21M NKFS Centre entirely on donated income (funded by the Shaw Foundation, the late Tay Choon Hye, Singapore Pools, Lee Foundation and Singapore Buddhist Welfare Services);</li><li>• Set up a Children's Medical Fund in 2004 for a range of chronic illnesses beyond kidney problems;</li><li>• Runs medical forums (eg. TransplantAsia conference for all transplant health professionals);</li><li>• Has just set up a dialysis unit in Samoa;</li><li>• Just launched a Cancer Fund in Singapore, linking with The Cancer Institute and National Cancer Centre and using NKFS experience in healthcare and community funding of healthcare to broaden its focus to another lifethreatening disease;</li><li>• Runs nonprofit management training through an innovative internship program through affiliations with Harvard, MIT, Stanford, London Business School and other premier MBA programs. Summer interns are taken on board and study at the NKFS Corporate University learning Strategic Management, HRM, Brand Management, Change Management, Advanced Management on Leadership and IT. Applicants propose a project they will undertake that will advance NKFS.</li></ul>

**More information:** <http://www.nkfs.org>

### Idea takeout:

- Model for a successful community health agency that has applied its expertise in one disease and networks to solving an even larger community health issue (cancer)
- Model of community subsidising healthcare in area where major lack was evident.
- Model of collaboration as community funding and healthcare expertise partner for medical institutes.
- Model for garnering international management linkages and input from bright management minds.

## 2.4 Israel

### Giving overview

Religion is a major factor that differentiates Israel's nonprofit sector (Gidron and Katz 1998, p.1). The link between religion and state and the aspect of Diaspora giving whereby Jews from all over the world contribute to Israeli causes make Israel a unique environment. Judaism has also fostered voluntarism and charity as part of its ethos. Diaspora giving, while still significant, has been decreasing. US reports for instance suggest that the younger generation of North American Jews do not feel the same connection to Israel their parents felt and hence giving to traditional Jewish organisations is down and younger Jews are more likely to support secular organisations. They also are seeking greater control over how their money is spent, such as through more direct giving to Israeli nonprofit organisations rather than through a third party organisation (<http://givingwisely.org/Intro2.htm>).

Giving from the US comes for instance from the Israel Humanitarian Foundation or the United Jewish Communities (a merger of the United Jewish Appeal, the Council of Jewish Federations and the United Israel Appeal). In 1999, this raised more than \$850m in the US and \$103m in Canada of which roughly 70% supports local Jewish needs and 30% goes to Israel. To answer this need, UJC created JVPFs - Jewish Venture Philanthropy Funds embracing 25 to 30 successful local entrepreneurs each investing \$10,000 in a fund. The supporters also invest their managerial talents to come up with innovative social solutions.

The Voluntary and Nonprofit Sector (VNPS), was established in 1986 as a nonprofit organization which serves as the umbrella organization of the voluntary and nonprofit organizations in Israel promoting transparency and professionalism. It runs particular programs for new and aspiring organisations and is funded by JDC-Israel, the Kahanoff foundation and by membership dues. Special projects are funded by contributions and grants received from other foundations. Listing of medically related nonprofits can be found at <http://www.doctor.co.il/zorganizationlink.htm> and <http://www.jr.co.il/hotsites/med-il.htm>.

While HMR is not separately delineated, the Johns Hopkins Comparative Nonprofit Sector Project (1995) pinpointed the 'education and research' and the 'health' sectors as Israel's largest nonprofit segments, both with high revenue from government (64% and 75% respectively) and low to moderate philanthropic revenue (12% and 3% respectively).

### Statistical and other information on medical research funding

Israel Life Science Industry is a group dedicated to researching, developing, and advocating policies and actions that promote biomedical science, biotechnology, Ag-Biotech and medical device innovation in the State of Israel (<http://www.ilsa.org.il>). It comprises medical device, biotechnology, pharmaceutical and medical service companies, universities and private research institutions, and providers of services to the industry such as venture capitalists, lawyers, accountants and incubators. ILSI reports Israel is ranked second and third in terms of number of publications in leading life science magazines per 100,000 inhabitants and senior faculty members per million inhabitants, respectively. Proactive approaches to funding form part of its objectives, specifically providing networking opportunities between companies, potential investors and other stakeholders.

ILSI charts some \$800M - one billion dollars spent by local industry and academia on life science research in 2004, sourced proportionately as 30.3% from government, 28.2% from venture capital, 27% from self-funding companies, 12.8% from competitive grants, 1.7% from binational government supported foundations. Since 1984, the Government has encouraged the growth of high technology industry through support and incentive programs. In some cases, income from approved enterprises attracts reduced tax rates and grants sometimes cover fixed asset costs. The Office of the Chief Scientist of the Ministry of Trade and Industry (OCS) provides grants of up to 50% of approved R&D budgets for specific project, subject to repayment through royalties on sales of products resulting. Some 21% of OCS grants to high-tech industries in 2003 went to medical devices and 14% to biotechnology.

The government has also funded a technology incubator program providing facilities, and guidance to scientists and companies with novel concepts. Israel is linked into bi-national R&D joint venture funds with the US, Canada, Singapore, Korea and England. Cooperation agreements exist with some EU members, China, Hong Kong and other countries, often creating arrangements where an Israeli company provides technology and the other partner supplies manufacturing and marketing components. A recent Government incentive is the Heznek Fund launched by the Israeli Ministry of Trade and Industry to encourage private equity funds to seed fund embryonic companies who would otherwise not locate funding. The Heznek Fund partners the private equity fund to establish the company then offers an attractive buy-out option to the private funder at the level of the initial investment by the Heznek Fund - not its increased value.

Venture capital funding in Israel life sciences achieved record levels in 2004, with 60% in the medical device field and the rest in biopharmaceuticals.

## 2.4.1 Israel Venture Network

Who:	A venture philanthropy fund
Where:	Tel Aviv, Boston and Silicon Valley
Why:	To initiate projects likely to create a long-term impact on Israeli society. Slogan: Venture practices to better Israel.
What:	Membership recruitment events have been held to raise a million dollar target. The goal is to create a network of US and Israeli based business leaders who personally fund projects in Israel. Voting rights costs \$25,000 pa and includes mainly individual but also corporate members.

Projects are in various fields (education etc) and often create partnerships between government, and existing private foundations. IVN does not seek to be a permanent funding source. It seeks to create change and then move on, having created what they call a 'viral effect'. A Fellows program operates whereby a stipend is paid for two years and Fellows are mentored by the entrepreneur members while working on IVN projects.

**More information:** (Neiman, R. (2002) 'Philanthropy as Start-up' Globes, December 10, downloaded 6/3/05; <http://www.ivn.org.il>)

### Idea takeout:

- Leveraging of Government input through partnerships with private and voluntary funders for a defined purpose and period.
- The targeting of young entrepreneurs for their ideas and commitment as well as their financing is a good model, and is based on the success that Israel has attained in hi-tech industries, second only to the US. The giving circle concept (similar to the SMILE Foundation) has worked well and has attracted significant leadership input from CEOs of major technology companies. The mentoring of the recipient organisation and personnel is also a useful idea.

## 2.5 Canada

### Giving overview

Philanthropy is described in Canada as 'big business', eclipsing the country's retail and agricultural industries and with a workforce equivalent to the manufacturing sector. The recent study, conducted by Imagine Canada and the Johns Hopkins Center for Civil Society Studies, shows that in proportion to its entire economy, Canada has the second-largest nonprofit sector, ahead of the US and behind only the Netherlands.

The sector boasts almost 7 percent of Canada's GDP and employs 12 percent of the country's eligible workforce, compared to 10 percent for the U.S. The study suggests Canadian nonprofits receive more government funding, than other nations, accounting for 51 percent of revenues.

Philanthropic promotional campaigns have operated prominently in recent years. The Imagine Campaign ran in similar vein to the UK's Giving Campaign and particularly targeted corporate giving. It has now evolved into the E-magazine campaign targeting entrepreneurs and internet giving.

### Statistical and other information on medical research funding

Federal and provincial governments are the largest research funders in Canada (Cairns 2004). Federal agency, the Canadian Institutes for Health (CIHR) is facilitating the creation of a Canadian Clinical Research Coalition of major stakeholders (including health charities), to provide the framework for collaborative strengthening of clinical research and a unified voice to convince governments and the public to increase the funding of clinical research.

A Canadian Survey of Giving and Volunteering has been conducted by Statistics Canada every few years since 1997. Part of the impetus behind this survey comes from Health Canada as well as charitable peaks like Imagine Canada (formerly the Canadian Center of Philanthropy). Some 78% of Canadians make financial donations and health causes receive 20% of these, although some 41% of Canadians give to health organisations. (Medical research is not noted separately). A Canadian Medical Discoveries Fund was established by the Medical Research Council (now run through the Canadian Institutes for Health Research) in 1994 to counter the shortage of venture capital. By 1998 it had funded some 30 start-ups. The Medical Research Council actively partners industry and nonprofits in its funding.

Canada is said to have a very attractive system of tax incentives for R&D and to continually be working on the path to get the tax environment right for its commercialization and diffusion (Conference Board of Canada, 2002, p.2). Initiatives discussed by the Conference Board of Canada include incentive tax deductions applied to the cost of purchasing patents, copyrights, and licence agreements to encourage technology transfer and application. Faster depreciation write-offs for capital assets with high rates of technological obsolescence have been another suggestion. Likewise, temporary relief in the form of lower corporate tax rates for firms that innovate has been mooted. Federal and provincial governments are pursuing targets for increased innovation, and investing in skills and R&D. More controversially, individual tax improvements have also been suggested, such as encouraging investment in specialised skill acquisition by making it fully tax deductible for an individual or rewarding highly qualified Canadians by offering them special income tax deductions for a specified time. A Canadian Collaboration Fund to support partnerships of small firms with their counterparts in Canada and internationally has been discussed, based on a tax incentive for collaboration.

Entrepreneurs and early-stage investors have urged better treatment of capital gains and employee stock options, especially full loss offset against the consolidated taxable income of an eligible investor so risk taking and entrepreneurship are not penalised. The Conference Board concludes that tax policies have a strong influence on the behaviour of entrepreneurs and corporations who are critical to driving innovation.

## 2.5.1 The Canada Foundation for Innovation (CFI)

Who:	An independent corporation created by the Federal Government.
Where:	Ottawa.
Why:	To fund research infrastructure and strengthen the capacity of universities, colleges, research hospitals and other nonprofit research institutions to carry out world class research and technology development.
What:	<p>CFI's budget of \$3.65 billion funds up to 40 percent of a project's infrastructure costs. Partnerships with institutions and their funding partners from the public, private, and voluntary sectors who provide the remaining 60 percent of a project's cost are crucial. Based on this formula, the total capital investment by the CFI, the research institutions, and their partners, will exceed \$10 billion by 2010.</p> <p>CFI support is intended to:</p> <ul style="list-style-type: none"><li>strengthen Canada's capacity for innovation;</li><li>attract and retain highly skilled research personnel in Canada;</li><li>stimulate research training of young Canadians;</li><li>promote networking, collaboration, and multidisciplinary among researchers;</li><li>ensure the optimal use of research infrastructure within and among Canadian institutions.</li></ul> <p>The research enabled by CFI support is also creating the necessary conditions for sustainable, long-term economic growth-including the creation of spin-off ventures and the commercialization of discoveries.' (<a href="http://www.innovation.ca">http://www.innovation.ca</a>)</p> <p>Funds include The Innovation Fund, New Opportunities Fund; Infrastructure Operating Fund, the Research Chairs Infrastructure Fund (aiming to create 2000 new university chairs), the Research Hospital Fund and two International Funds for joint ventures.</p>

More information: (<http://www.innovation.ca>)

### Idea takeout:

- Leveraging of Government input through partnerships with private and voluntary funders for a defined purpose and period.

# 3. Australian Models of Philanthropy for Health and Medical Research

## 3.1 Giving overview

Several sources document that the Australian philanthropic landscape is burgeoning. The latest and most comprehensive study of Australian giving of time and money (Giving Australia) was funded by the Prime Minister's Community Business Partnership and released in October 2005. It reports total giving of \$11 billion pa comprising \$7.7 billion from individuals and \$3.3 billion from businesses. Tsunami giving was quarantined from these figures. The increase in individual donations from 1997 in absolute terms is 88%, and when inflation-adjusted reflects a rise of 58% in seven years. Some 87% of Australians are estimated to have given to community causes in the year to January 2005 with an average donation of \$424 (median donation \$100). This compares with the US average contribution of US\$1,075 per household (Independent Sector 2001).

Some \$2 billion of the individual donations came in the form of 'charity gambling' or support for events. In the 2003-4 financial year, 67% of businesses gave, using a variety of channels and to a total amount double that reported in the ABS Generosity of Australian Business survey in 2002. Donations accounted for 58% of business giving, sponsorship 25% and community business partnerships 17%. In individual giving, religious institutions (ie. spiritual organisations not including the many community welfare service organisations run by faith-based groups) were most heavily supported dollar wise, representing 36.1% of all donations. Community service and welfare organisations win the highest number of givers overall but the donation amount given by these supporters is among the smaller dollar amounts. Businesses supported community service and welfare organisations most readily, with 53% of businesses giving to these causes and at a rate of nearly \$1 billion pa, or some 30% of all business giving. This sector also attracted more than a quarter of all volunteering hours.

Trends are also studied by tracking the flow of tax deductible donations by individuals. Steady growth likewise has been the byword in these statistics, with tax deductible donations increasing by an average of 6% per annum according to QUT's Centre of Philanthropy and Nonprofit Studies, which has charted the levels of tax deductible donations since 1978-79. Higher income earners are likely to be more generous according to the tax deductibility statistics and Giving Australia. The more one earns, the more one claims as a tax deductible donation. QUT reports donors earning more than \$1 million per year claimed an average of \$40,867 in tax deductible donations in 2002-3, some 1.4% of their taxable income (compared with the average for individual taxpayers of approximately .26 of their income). These higher earners were also more likely to make and claim a tax deductible gift, with 64% in this tax bracket doing so, compared with the national average of 34.92% of Australian taxpayers. Good response has been noted by these potential major givers to philanthropic incentives including the creation of Prescribed Private Funds (PPFs) (similar to US family foundations) and expansion of the type of gift that may be tax deductible to include property valued by the Commissioner of Taxation at more than \$5,000. More than 300 PPFs have now been established, by individuals, families and companies. Streamlined employee payroll giving and conservation covenants over land tax deductions are also believed to have encouraged the increased overall giving.

In the USA, 2004 giving represented 1.6% of Gross Domestic Product. Canadian giving in 2000 was equivalent to 0.46% of GDP. With Australian giving at 0.68% of GDP and taking into account the different sizes of the economies, the USA can be seen to generate more than twice the level of Australian giving while Australians give about one and half times as much as Canadians on average.

According to Philanthropy Australia (<http://www.philanthropy.org.au>) at least 2,000 trusts and foundations are estimated to exist in Australia, disbursing up to one billion dollars each year, based on total combined estimated assets of ten billion dollars. This compares with the 88,509 US foundations with a total asset base of approximately \$500 billion, with giving of \$27.6 billion (Independent Sector 2001). The UK has some 10,900 private trusts giving some two billion dollars each year (Association of Charitable Foundations website <http://www.acf.org.uk>).

Lyons and Hocking (2000) chart the nonprofit sector itself as large, with as many as 700,000 organisations, many of whom are small and entirely voluntary. Approximately 35,000 of these employ staff and 20,000 have Deductible Gift Recipient Status.

In 1999/2000, the sector encompassed 6.8% of Australians in employment (similar to the US figure and larger than the UK and most European countries), contributed 3.3% to GDP and contributed to the economy at a level equal to the agricultural industry and twice the level as the entire economic contribution of Tasmania. When volunteering is added into this equation, the sector's economic contribution exceeds that of the mining industry. About a third of its income came from government grants and contracts.

Some key organisations active in the Australian philanthropic sector include the Prime Minister's Community Business Partnership, the Centre for Australian Community Organisations and Management (CACOM) at the University of Technology Sydney, QUT's Centre of Philanthropy and Nonprofit Studies, Philanthropy Australia, the Asia-Pacific Centre for Philanthropy and Social Investment at Swinburne University, Fundraising Institute Australia, the Association for Development Professionals in Education, the National Roundtable of Nonprofit Organisations, and Nonprofit Australia Limited.

## 3.2 Statistical information on HMR giving

Giving Australia reports solid and growing support for HMR causes. Health nonprofits (including medical research organisations) attracted one in seven of all individual donation dollars, one-tenth of all hours volunteered and nearly one in five dollars donated by business. Health nonprofits are second only to religious causes in winning individual donations but not a close second. As mentioned above, 36.1% of Australians donated to religious institutions while 14.2% of Australians support health causes, including medical research. While comparisons need some qualification because of some methodological changes, this represents a 19% rise from the 11.9% supporting health in the 1997 ABS study of giving. Giving Australia pointed to the power of affiliation (ie. some form of membership or direct volunteering involvement) in generating a higher donation amount across the various cause areas. In medical research, 30.4% of supporters in this area reported such an affiliation and gave an average donation of \$94 pa compared with the average donation of \$77 pa by 'non-affiliated' supporters. In health services non-affiliated givers gave an average \$65 pa donation compared with their affiliated counterparts giving \$88 pa. In volunteering, health attracted 10.3% of the total hours volunteered by Australians, with 3.4% of this going to medical research and 6.9% to health services. Average hours of volunteering were higher for the health services sector at 126 hours pa against 51 hours pa average given to medical research. Unprompted awareness of health and disability charities is quite uniform across most capital cities, but lowest in Brisbane and Perth (McNair Ingenuity 2003). Female giving to religion, research, health, international aid and environment/animals is much higher than the male counterpart (Lyons and Hocking 2000).

### 3.3 Juvenile Diabetes Research Foundation

- Who:** An independent Australian non-profit, affiliated to the Juvenile Diabetes Research Foundation International. Largest non-Government funder of diabetes research in the world.
- Where:** Australia (independent company but linked to global organisation)
- When:** Established 1984 in Australia.
- Why:** JDRF's mission is to find a cure for type 1 diabetes and its complications through the support of medical research. JDRF funds the best and most promising medical research globally to this end.
- What:** JDRF directs funds to medical research in Australia from a wide range of sources. JDRF achieves this through a coordinated approach to marketing Australian research expertise, and JDRF's early stage medical research review process effectiveness, to attract significant global and local medical research investment.

JDRF's funding activities include:

- Partnerships with the NHMRC: JDRF has a suite of co-funded partnerships with the NHMRC, such as the Australia 2 Special Program Grants and the Diabetes Vaccine Development Centre, to a total of over \$25m
- Partnership with the Government direct: JDRF has been engaged to implement an islet transplantation program, with support of \$30m over four years provided direct to the organisation. JDRF will apply its best practice medical research review process to ensure effectiveness and efficiency.
- Direct investment from international sources: JDRF International provides around \$6m additional to that raised in Australia annually from international sources to medical research in Australia. JDRFA also has attached funds from overseas foundations, such as the Western Union Foundation
- Local private philanthropic funding: Contributions from individuals, such as \$5m towards the islet transplantation centre by Sue Alberti. Contributions from local foundations directly towards research projects, such as \$25k towards a separate islet project in Westmead
- Local corporate support: Through events and partnerships, direct support for medical research in Australia of around \$2.5m annually net of costs

**More information:** [www.jdrf.org.au](http://www.jdrf.org.au)  
[www.jdrf.org](http://www.jdrf.org)

#### Idea takeout

- Diversified portfolio of funding sources and models provides the ability to support a range of research projects at different stages
- Quality and global perspective of research selection and review process (determinant of outcomes) provides promise of efficiency of investment
- Strong use of partnerships with key Government funders

### 3.4 SMILE Foundation (Supporting Medical Innovation for Life Enhancement)

- Who:** Lyndall and Malcom Beville have health care marketing and business/property development backgrounds and a strong history of successful biotech investment. Others involved are a small group (5-10) like-minded founding members.
- Where:** Sydney Australia
- When:** Soft launch of SMILE (November 2004)
- Why:** Believe they live blessed lives so want to do something good, and supporting medical research is logical given to the business sector and is differentiated from other investment/granting vehicles by credible contacts in the business community, sound business language and commercial nous.
- What:** To fund research expertise through strategic investment and leave an endowment that will continue to fund research through the generations.
- The fund is incorporated as an Institute for promotion of health.
  - Have only had soft launch so far to gauge the market reaction. Received positive feedback for concept.
  - Founding members provide seed funds, a proportion of which will be donated annually to medical R&D and the remainder invested in promising Australian medical/biotech companies. Profits will be reinvested in the charity to perpetuate and grow its corpus and keep it self funded long term.
  - Aim for future is to be the largest private grant giving body, eventually dealing in infrastructure for a major healing and treatment centre. Would like to open the fund to the public eventually with a major awareness raising event seeking donations directly into grants rather than the core investment.
  - Have adopted a different structure from other funds which do not provide enough flexibility with the investment portfolio because only a small percentage is able to go into the biotech sector.
  - Taxation structure is not like any other fund so need special consideration, including for tax deductible donations and exemption of tax on benefits because in no personal benefit to investor.
  - Small group of founding members/investors allows flexibility and keeps administration costs to a minimum, including having the next generation running the fund one day.
  - SMILE will take responsibility for which applications are chosen for funding and give assurance to investors. This is different from some other 'Giving circles' which help people give, but are random in approach.
  - Accept that while they may lose money along the way, believe the concept is realistic and that there is money to be made for medical research.
  - Big plans for major launch - personal friend who is pianist and composer to compose a concerto specifically for event with Sydney Symphony Orchestra at Opera House, with fund receiving percentage of ticket sales and royalties.

**More information:** <http://www.smilefoundation.com.au>

#### Idea takeout

- Australian venture philanthropy/giving circle approaches may have potential.

## 3.5 Macquarie Bank Foundation

- Who:** Chairman: Mr David Clarke, Chairman Macquarie Bank  
Director: Hon. Warwick Smith, Executive Director Macquarie Bank  
Director: Mr John Green, Executive Director Macquarie Bank  
Director: Ms Sheryl Weil, Division Director Macquarie Bank  
Head: Mrs Julie White
- Where:** Based in Sydney, but provides funding internationally. Specifically concentrating on areas where Macquarie offices are located.
- When:** Has been involved in community giving since 1969. The Foundation was formalised in 1984
- Why:** Macquarie has a simple belief that it is a member of the society in which it operates and it follows that one of its important duties is to work for the betterment of that community.
- What:** Finding inspired solutions to difficult problems is one of the cornerstones of Macquarie Bank and this philosophy is synonymous with the approach and work of the Macquarie Bank Foundation.

The Macquarie Bank Foundation focuses its resources in six core areas - the arts, education, environment, health care, health research and welfare. It is also committed to the development of projects specifically aimed at our indigenous communities.

The Foundation looks for opportunities that are innovative and that are genuinely responsive to the community's needs.

### Health Research:

The Foundation supports many medical research initiatives through a range of health organisations which recognise the achievements of researchers and assist them in developing their work.

Asthma Foundations of Australia, National Breast Cancer Foundation, Cure Cancer Australia, The National Heart Foundation and MS Research Australia are examples of some of our major partners.

Funding is provided to health research foundations to enable them to allocate research grants to appropriate programs.

In addition, the Foundation matches all donations and funding undertaken by staff for community programs.

- How:** The Foundation's funding criteria are flexible and open. We welcome applications for funding from a diverse range of community based initiatives that are working innovative ways to provide long term benefits.

Each application is assessed on its individual merit  
All applications are formally reviewed quarterly.

- More information:** [www.macquarie.com.au](http://www.macquarie.com.au)

## 3.6 The Garnett Passe and Rodney Williams Foundation

<b>Who</b>	<p>The Foundation was established by the late Mrs Barbara Williams on 26 February 1986 by a Deed of Settlement to honour the memory of her two husbands, Garnett Passe and Rodney Williams.</p> <p>When Edward Roland Garnett Passe graduated in Dentistry from the University of Melbourne in 1926 before travelling to the United Kingdom to study Medicine. He specialised in Otolaryngology and gained considerable eminence, notably as a pioneer in the surgical treatment of deafness. His career was interrupted by service with the Royal Navy in World War II, after which he very quickly established himself as an outstanding Otolaryngologist with an international reputation. As well as being a superb surgeon, he was an excellent sportsman with a serious interest in sculpture. He married Barbara Hope Slatter in 1939, but died thirteen years later as a relatively young man, in 1952, aged 48.</p> <p>Rodney Wellington Williams, born in 1892, of New England ancestry, was educated at Yale University and became a stockbroker with the New York Stock Exchange. Like Garnett Passe, he was an enthusiastic and multi-talented sportsman, but also had a keen interest in Art and Historical Preservation, becoming actively involved in a number of historical societies and associations. He married Barbara Passe (nee Slatter) in 1968, but died some sixteen years later, in 1984, aged 91.</p> <p>The Foundation became operative upon the death of Mrs Williams on 16 September 1991.</p>
<b>Purpose</b>	To advance the Specialty of Otorhinolaryngology and the related medical, surgical and paramedical fields in Australia and other countries. A number of fellowships, scholarships and grants have been established to facilitate the achievement of this purpose.
<b>Eligibility</b>	Depending on the award, applicants must be medically qualified, science graduates with recognised post-doctoral achievements, practising Otolaryngologists or trainees in the Specialty.
<b>Category Field</b>	Research or clinical Otology Audiology Rhinology Olfaction Head and Neck, Oncology and Laryngology Vestibular Function
<b>Funding</b>	Salaries, minor items of equipment and consumables
<b>Exclusions</b>	Usually commitments will not be made in which continued support over many years is implied Annual distribution Approx. \$2.5 million
<b>Total distributions</b>	Approx. \$23 million

Further information:

The Secretary  
The Garnett Passe and Rodney Williams Memorial Foundation  
PO Box 577  
East Melbourne VIC 8002 Australia

Telephone (+61 3 9419 0280)  
Facsimile (+61 3 9419 0282)  
Email gprwmf@bigpond.net.au

# Bibliography

Acs, Zoltan J. and Dana, Leo Paul (2001) 'Contrasting two models of wealth redistribution,' *Small Business Economics*, Vol. 16, Iss. 2, March 2001, p.63.

Agency for Science, Technology and Research (2005) <http://www.a-star.edu.sg/astar>, accessed 4 June 2005.

American Association for the Advancement of Science (1999) *How to Fund Science: The Future of Medical Research*, Maryland, Feb. 14 - 16, 1999, <http://www.aaas.org/spp/cstc/pne/pubs/fundscience/findings.htm>, accessed 20 February 2005.

American Association of Fundraising Counsel (AAFRC) Trust for Philanthropy (2003) <http://www.aafrc.org> accessed 8 April 2005.

Anderson, Linda (2004) 'Dollars 120m gift for SMU,' *Financial Times*, 10 May 2004, p.12.

Auge, Karen (2001) 'National Jewish given \$25 million Research building to be named for benefactor,' *Denver Post*, 13 July 2001, p.B01.

Bank, David (2003) 'Larry Ellison Has A Science Project: Courting Biologists --- Founder of Oracle Corp. Funds Research and Entertains; "Guess I'm a Groupie",' *Wall Street Journal*, 9 Jan. 2003, p.A1.

Berman, Phyllis (2002) 'A motivated philanthropist,' *Forbes*, Vol. 170, Iss. 6, 30 Sept. 2002, p.90.

Billitteri, Thomas J. (2000) 'Venturing a Bet on Giving,' *The Chronicle of Philanthropy*, 1 June 2000, Gifts and Grants section.

Bosch, Xavier (2002) 'Europe pumps more funds into new biomedical research programme,' *The Lancet*, London, 23 Nov. 2002. Vol. 360, Iss. 9346, p.1672.

Bosch, Xavier (2003) 'Spain offers helping hand to hospital researchers,' *Science*, Washington, 17 Oct. 2003, Vol. 302, Iss. 5644, p.369.

Butcher, James (2003) 'Funding needed for European neuroscience,' *The Lancet*, London, 27 Sep. 2003, Vol. 362, Iss. 9389, p.1049.

Cairns, John A. (2004) *The Canadian Clinical Research Initiative: transforming Canadian clinical research capacity*, *Clinical and Investigative Medicine Ottawa*, Dec. 2004. Vol. 27, Iss. 6, p.292-295.

(2005) 'Canadian Nonprofits,' *Philanthropy Journal*, Vol. 6 No. 15 [news@philanthropyjournal.org](mailto:news@philanthropyjournal.org) email news service 11 April 2005.

Chua, Vincent C. H., and Wong, Chung Ming (1999) *Tax incentives, individual characteristics and charitable giving in Singapore*, *International Journal of Social Economics*, Vol. 26 No. 12, p.1492.

Collinson, Simon and Copolov, David L. (2004) 'Challenges and opportunities for mental health research in Australia,' *Journal of Mental Health*; Feb. 2004, Vol. 13 Issue 1, p29.

Community Wealth Ventures (2000) *Venture Philanthropy: Landscape and Expectations*, Morino Institute.

Couzin, Jennifer (1998) 'New funds for diabetes studies,' *Science*, Washington, 18 Sep. 1998. Vol. 281, Iss. 5384, p.1795.

Crowley W.F. Jr, Sherwood L., Salber P., Scheinberg D., Slavkin H., Tilson H., Reece E.A., Catanese V., Johnson S.B., Dobs A., Genel M., Korn A., Reame N., Bonow R., Grebb J., Rimoim D. (2004) 'Clinical research in the United States at a crossroads: proposal for a novel public-private partnership to establish a national clinical research enterprise,' *Journal of the American Medical Association*, Vol. 291, Iss. 9, March 3, 2004, p.1120.

Daniels, Cora, Burke, Doris, Neering, Patricia (2004) 'The Man Who Changed Medicine,' *Fortune*, Vol. 150, Issue 11, 29 November 2004.

Eliot, Marshall (1998) 'Kansas City Institute's big plans,' *Science*; 04/17/98, Vol. 280 Iss. 5362, p370.

Field, Robert I., Plager, Barbara J., Baranowski, Rebecca A., Healy, Mary Anne and Longacre, Margaret L. (2003) 'Towards a policy agenda on medical research funding: Results of a symposium,' *Health Affairs Chevy Chase May/June 2003*. Vol. 22, Iss. 3, pp.224-230.

Fisher, Paul Graham and Buffler, Patricia A. (2001) 'Malignant Gliomas in 2005: Where to Go From Here?' *Journal of American Medical Association*, Vol. 293, Iss. 5, Feb. 2, 2005, p.615.

The Foundation Center (2005) [http://www.fdncenter.org/research/health\\_research](http://www.fdncenter.org/research/health_research).

Fulton, Katherine and Blau Andrew (2005) *Cultivating Change in Philanthropy*, Global Business Network and Monitor Institute, p.5. <http://www.fuqua.duke.edu/centers/case/articles/0805/corner.htm>

Goodson, Marvin (1995) 'Private medical research organizations: Long-term research funding source for non-profit hospitals,' *Tax Management Estates, Gifts and Trusts Journal*, Vol.20, Iss. 2, March 9, 1995, p.75.

Grantmakers in Health (2005) *Building Relationships in Health: How Philanthropy and Government Can Work Together*. Washington DC.

Greenberg, Daniel S. (1997) 'Another boost for US biomedical research,' *The Lancet London*, 13 Sep. 1997. Vol. 350, Iss. 9080, p.791.

Gruman, Jessie and Prager, Denis (2002) 'Health Research Philanthropy in a Time of Plenty: A Strategic Agenda,' *Health Affairs*, Vol. 21, No. 5, pp.265 - 269.

Gura, Trisha (2001) 'Biomedical philanthropy, Silicon Valley style,' *Nature* Vol. 410, No. 6825 March 8, 2001, p.140.

Gruman, Jessie and Prager, Denis (2002) 'Health research philanthropy in a time of plenty: A Strategic agenda,' *Health Affairs Chevy Chase, Sep/Oct 2002*. Vol. 21, Iss. 5, p.265-269.

Gundersen Lutheran Medical Foundation (2005) *Financing Research Through Philanthropy*, <http://www.gundluth.org> accessed 29 March 2005.

- Halstead, Larry. (2003) 'Grants, donations, cash propel medical research,' *The Business Journal Tampa*, 7 Nov 2003, Vol. 23, Iss. 45, p.14.
- (2005) 'Harvard medical set to research aging' *Boston Globe*, 11 March 2005, p.B2.
- Hira, Nadira A. (2004) 'How big givers are shaping other quests for cures,' *Fortune*, 11/29/2004, Vol. 150 Issue 11, p.100.
- Hood, John (1996) 'How corporate profits deliver social good,' *Consumers' Research Magazine*; Aug. 1996, Vol. 79 Iss. 8, p.10.
- (2003) 'In praise of Gates,' *Nature*, London, 2 Oct 2003. Vol. 425, Iss. 6957, p.435.
- The Institute for the Study of Aging, Inc. (2005) <http://www.aging-institute.org/> accessed 7 July 2005.
- Jones, Roseann Murphy (1997) *The pursuit of knowledge and the business of science: The transition of research at United States academic health centers and economic implications for bioscience policy*. Doctoral Thesis, University of Pennsylvania.
- Kowalczyk, Liz (2001) 'A New Neely Cancer Fund Will Compete For Donors,' *Boston Globe*, May 25, 2001, p. A1.
- Lehmann, Volker (2001) 'New developments for public-private partnerships in drug development,' *Biotechnology Monitor*, Vol. 46, June 2001.
- Lyons, Mark and Hocking, Susan (2000) *Dimensions of Australia's Third Sector*, Centre for Australian Community Organisations and Management, UTS, Lindfield.
- Mandel, H. George and Eliot S. Vesell (2004) 'From progress to regression: biomedical research funding,' *Journal of Clinical Investigation*, Vol. 114, pp.872-876.
- McCormack, Scott (1999) 'Medical Portfolio,' *Forbes*, Vol. 163, Iss. 11., 31 May 1999, p.134.
- McGovern, Victoria and Bond, Queta (2003) 'Global health research,' *Science*, Washington, 27 Jun. 2003. Vol. 300, Iss. 5628, p.2003.
- McKivergan Daniel (1999) 'Engineering Progress: How two foundations are helping build the future of medicine,' *The Philanthropy Roundtable*  
<http://www.philanthropyroundtable.org/magazines/199-07/mckivergan.html> accessed 29/3/05.
- Meyers, Roy T. (1999) 'Federal Financing for Medical Research Through Trust Funds and Entitlements' presented at *How to Fund Science: The Future of Medical Research Maryland*, Feb. 14 - 16, 1999, American Association for the Advancement of Science.
- Ministry of Community Development, Youth and Sports (2003) <http://app.feedback.gov.sg/> accessed 8 April, 2005
- Moos, Bob (2004) 'Dallas philanthropist's gift allows Texas medical center to hire top oncologist,' *Knight Ridder Tribune Business News*, 7 Dec. 2004, p.1.
- Moran, Susannah (2005) 'Poor marks for Australia's rich,' *Australian Financial Review*, March 8, 2005, p.59.
- National Kidney Foundation Singapore (2005) <http://www.nkfs.org/main.htm> accessed 8 April 2005.
- Neiman, Rachel (2002) 'Philanthropy as Start-up,' *Globes*, Dec. 10, 2002.
- Ogilvie, Dame Bridget (2000) *Address to ASMR Medical Research Week*. Canberra; 2000.  
<http://www.asmr.org.au/mrw/dbo2000.html> accessed 29/3/05.
- Philanthropist or commercial opportunist? *The Lancet*, London, Vol. 360 No.9346, p.1617.
- Philanthropy Australia (2005) <http://www.philanthropy.org.au> accessed 4 June 2005.
- Pincock, Stephen (2004) 'Medical research receives financial boost,' *The Lancet*, London Mar 27, 2004. Vol. 363, Iss. 9414, p.1041.
- Pincock, Stephen (2004) 'Britain's brain gain,' *Lancet*; London 7 Oct. 2004, Vol. 363 Iss. 9429, p.127.
- Scheff, Joanne (2001) 'The Private Sector's Support for the Arts: The US Experience' Paper presented at *Seminario Internacional: Inversion Cultural Los Nuevos Escenarios March 2001*, Caracas.
- Peter Schworm (2005) *Hospital Receives \$6M for Stem Cell Research*, *Boston Globe*, March 14, 2005, p.B2.  
(2005) 'Sector is big business, dwarfing country's retail industry, study says,' *Philanthropy Journal*  
<http://www.philanthropyjournal.org/newsarticle/4/7/2005>.
- Sewell, Tim (1994) 'Helping hands: Memphis businesses large and small are finding ways to make a difference in the community,' *Memphis Business Journal*, Vol. 16, No. 34, 26 Dec. 1994, p.25.
- Sher, Hanan (2004) 'Is small beautiful?' *The Jerusalem Report*, 23 August 2004, p.30.
- Staropoli, John F. (2003) 'Funding and practice of biomedical research,' *Journal of American Medical Association*, Chicago 2 Jul. 2003. Vol. 290, Iss. 1, p. 112.
- St John, Warren (2002) 'Cash Aside, Is That Prize Meaningful?' *New York Times*, 7 May 2002, p.B7.
- Swan, Norman (2000) *Medical Research Investment Fund*, *The Health Report*, 22 May 2000, Radio National.
- Teltsch, Kathleen (1992) 'New York Research Program Lures Scientists', *New York Times*, May 29, 1992, p.136.
- Townsend, Lindsey. (2002) 'Corporations fund cutting-edge research,' *Dallas Business Journal*, Dallas, 26 Apr 2002. Vol. 25, Iss. 38, p.26.
- Venture Philanthropy Partners (2005) *Venture Philanthropy in Biotechnology and Drug Development* accessed 29 March 2005, <http://www.sbtdc.org/technology/philanthropy.htm>
- Verespej, M.A. (1996) *Gutsy decisions of 1995: Philanthropist extraordinaire*. *Industry Week*, Vol. 245(2) 22 Jan. 1996, p.26.
- Vesell, Elliot S. (2004) *Journal of Clinical Investigation*, Oct. 2004, Vol. 114 Iss. 7, p.872.
- Giving Australia  
<http://www.innovation.ca>

**Research Australia Limited**

Exchange Centre 20 Bridge Street Sydney NSW 2000

Telephone 02 9227 0875 • Facsimile 02 9227 0800 • Email [enquiries@researchaustralia.org](mailto:enquiries@researchaustralia.org)

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