# Investing in the **MS Breakthrough**



#### Investing in the MS Breakthrough

# Finding the cause and a cure for Multiple Sclerosis

Australia's MS scientists have the will, the skill and a commitment to work together across the nation. We now need serious financial resources to turn an ambitious goal into a scintillating Australian success story.



"It's as simple as this – without MS research there is no cure.

Anyone with multiple sclerosis would welcome even the smallest improvement in their quality of life.

I dare you to tell me that we shouldn't keep trying for an answer!"

Shani Diagnosed aged 30

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#### Help us find the cure

Multiple Sclerosis is the most common neurological disease affecting young Australians today. It is a condition that debilitates many young adults in the prime of their lives, and for the rest of their lives.

There are over 15,000 people with MS in Australia. Nearly everyone knows someone suffering with MS. Over 1,000 more will be diagnosed in the coming year.

"Betty has been in Canberra as the guest of honour at the launch of a campaign by MS Australia to raise some \$30 million over five years to tackle the causes of, and hopefully find a cure for, multiple sclerosis.

I announced on behalf of the Commonwealth government a contribution of \$250,000 to the campaign. That is in addition to support over quite a period of years, embracing governments of both sides of politics, towards MS research through the National Health and Medical Research Council."

The Hon John Howard, Prime Minister – August 2004



Betty Cuthbert & The Hon John Howard, Prime Minister at the launch of MS Research Australia.

From diagnosis onwards, people with MS have to live with the uncertainty of when the next attack will come, and how bad it will be. It may leave them paralysed, blind or numb over a large part of their body. Day to day, they just don't know whether tomorrow will be the last day they will be able to walk or see or feel properly.

Recent exciting developments in MS research have brought us closer to a cure than ever before. Multiple Sclerosis Australia Limited (MS Australia) plays an important role in fostering research across a range of scientific disciplines and we believe the time is now right to leverage these recent advances.

With new financial partners from the public, corporate and philanthropic sectors, Australian scientists can substantially raise the medical research bar – and break through towards a cure for MS.

By joining us in the development of Multiple Sclerosis Research Australia, you will have the opportunity to play a pivotal role in the future lives of millions of people around the world. On the global stage, Australians are renowned for our world class talent in scientific neurological research. Through this bold, new approach, we are challenging the rest of the research world to follow our lead. We have set the goal of raising \$30 million to enable us to provide MS researchers with sufficient ongoing direct funding for the next ten years.

MS Australia strives for a world without Multiple Sclerosis. We endeavour to achieve this through our mission: seek the cure; provide the care.

As President of MS Australia, it is my great pleasure to invite your support and involvement in this significant new research initiative. I look forward to welcoming you to our journey and helping achieve a significant breakthrough for MS.



2.0

Graham Tribe President, MS Australia

#### Living with MS

#### "Dare to be remarkable"

s her tears soaked through his shirt, Simon reassured his broken child. "Don't worry darling, they'll find something soon, just you see." Rachel was typical of many newly diagnosed with MS. First shock, then disbelief, then fear. And Simon was typical of the hundreds of thousands of fathers, mothers, brothers, sisters, friends and relatives, hoping that "they" would find a cure, and find it soon. Ten years on and MS has robbed Rachel of her arms, her legs, her eyes and her dignity. She can still cry though.

Imagine your child in the prime of his or her life. The hopes, the plans, the dreams. Then comes MS. No one knows what caused it. No one knows how bad it will be. So where is this elusive cure? Where are those magnificent minds that will solve the mystery that is MS? Where are "they"?

"They" are everywhere; they are the teams of under-resourced scientists that make up the bulk of the medical research world. Somewhere amongst them are those with remarkable minds, ready and waiting to answer the key questions relating to MS.

You'd have thought the big questions have all been answered and that we're just filling in the gaps now. Not true. **We need your help**.

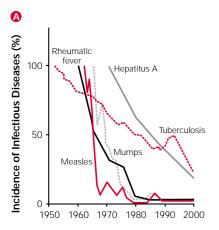


"It is so important for young people like me to know about research because it gives us hope which is so important – that one day there will be a cure and an MS-free world."

Jess Diagnosed age 28

#### MS – dramatically increasing:

The rise in autoimmune diseases (including MS) in the last 50 years has been steep, and according to research by Bach et al (2002), has risen even more steeply in the past 20 years. These graphs highlight the urgent need to invest in research to get these conditions under the same control as the infectious diseases. Figure 1 shows the comparative incidence of the two groups of diseases.



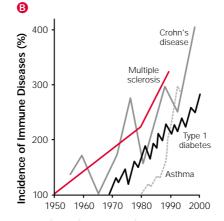


Figure 1: Relation between the Incidence of Infectious Diseases (A) and the Incidence of Immune Disorders (B) from 1950 to 2000 (Mechanisms of Disease: The Effect of Infections on Susceptibility to Autoimmune and Allergic Diseases [review Article] Bach, Jean-Francois. The New England Journal of Medicine Vol 347(12) pp911-920, 2002.

#### The mystery of MS

#### So what is MS?

Ultiple Sclerosis (MS) is a disease of the central nervous system. It is a chronic and progressive disease, for which there is as yet no known cure.

The cause of MS is still not known, although much has been learnt of the role of the immune system in the development of the disease. MS damages the protective myelin covering of the nerve fibres in the central nervous system and many of the nerve fibres themselves, causing "sclerosis" (scars) in the brain and spinal cord. This causes disruption to nerve transmission and affects many functions of the body. The symptoms of MS can be devastating. They include blurred vision and blindness, paralysis, poor coordination, extreme fatigue and problems with memory and concentration.

Although MS is not usually fatal, sufferers face the constant uncertainty of when an MS attack will occur, as well as how severe and how permanent these symptoms will be.

As yet, no drug can cure MS, but advances in research have meant that the progress of the disease may be slowed and that many of the symptoms can now be successfully managed and treated. We are now closer than ever before to understanding the disease and finding a cure....

So what are the big questions in MS research? Really there are only four:

- 1. What causes MS?
- 2. How can we stop it?
- 3. How can we reverse it?
- 4. Can we improve the lives of those already diagnosed with MS?

Question 1 may not only lead us to the cure but may help us prevent MS happening in the first place. Questions 2 and 3 address the cure. Question 4 looks to the here and now.

#### 1. What causes MS?

This is one of the great medical mysteries. If a clear cause of MS can be found, it will be a massive step towards finding effective therapies. For example, we know that AIDS is caused by a virus (HIV) and as a consequence a host of anti-viral studies have yielded drugs that are helping to save and prolong many lives.

But MS isn't that simple. If it were just a virus, it would have been found long ago. So are there any clues? Well, for a start, we know that the closer we are to the equator, the less the chance of MS. Why? The size of Australia's continent gives us the unique opportunity of examining this in detail.

So what does the apparent influence of latitude tell us? That there's something in the environment that is a cause, a germ that is more or less common as the latitude changes? Or it could just be a contributing factor? Could some innocuous viral or bacterial infection have left a little time bomb behind? Or in some perverse way do some infections make people less likely to develop MS? On the other hand, the extent to which we are exposed to UV light in childhood may afford some, as yet, unexplained protection.

And what about the genetics of people with MS? Has some ironic twist in genetic fate made many people uniquely susceptible to MS? In MS it is the body's own immune cells that attack the brain's neuro-support (glial) cells. Is there something in the genes of glial cells that makes them invite their own destruction? Or is the problem with the immune cells? We are now closer than ever before to understanding the disease and finding a cure....

The size of Australia's continent gives us the unique opportunity of examining this in detail.



"Hearing about new discoveries and research provides me with hope that one day when I go to the neurologist, he will tell me that the cure has been found.

The results of the current research have improved my life so much. About 18 months ago, I was not able to balance on a bike and now I am planning to ride 450 kilometres through China. Research and discoveries have improved my standard of living no end."

Michael Diagnosed age 21

#### MS: How can we stop it? reverse it? improve lives?

....we are fortunate to have some of the best immunology experts in the world here in Australia.

Australia has world-class expertise, in stem cell therapy.... Australia has world-class expertise in immunology, genetics, neurobiology and integrated medicine. But each of these fields is so vast, no individual can hope to be an expert in all of them. We plan to harness and direct this spread of expertise through our commitment to a fresh, lateral, and cross-disciplinary approach to MS research. This will bring all our Australian ingenuity to bear on a problem that has had the world stumped since MS was first scientifically described back in 1868.

#### 2. How can we stop it?

Like MS, the cause of diabetes is unknown. Yet, for many people, the effects of diabetes can be held in check for decades with a managed diet and insulin therapy. So even without knowing the exact cause of MS, we might still be able to find its choke points. There has already been a start. Interferon beta is the first drug that helps to slow down the progression of MS. Various alternative therapies are also reputed to slow down the progression of MS, although there is no reliable validation as yet. Is there a role for a more integrated medical approach to improving the lives of people with MS? What if the illusive needle is hidden in this haystack?

Mainstream or alternative, the challenge now is to find the choke points of MS – wherever the leads come from.

So where might these choke points be?

If we can stop immune cells attacking, this would halt the disease in its tracks. How can we do this? There are many potential strategies, all of which require fundamental knowledge of how the immune system works. And we are fortunate to have some of the best immunology experts in the world here in Australia.

#### 3. How can we reverse it?

This is the Holy Grail of MS and many other degenerative diseases, including spinal cord injury. The body has some amazing restorative capabilities. We are only just beginning to gain an understanding of the way stem cells can be manipulated. The amazing thing about stem cells is that under the right circumstances they may be persuaded to grow and mature into replacement skin cells for burns, replacement immune cells for leukemia, and yes, even replacement glial cells for MS.

Again, Australia has world-class expertise in stem cell therapy, and also the molecules that persuade the cells to grow and mature into different cell types – known as growth factors.

And in translating the results of MS research into real therapy, Australia is fortunate to have an internationally recognised clinical trial base – which not only supports local research, but is now increasingly attracting interest from overseas.

### 4. Can we improve the lives of those already diagnosed with MS?

This question is one that is being answered every single day by the hundreds of people that work with and for the MS Societies of Australia. From physiotherapy to psychological support to help in maintaining a high level of personal fitness and a positive self image to advocacy, many people with MS are receiving continuing support in their battles with the disease. Recognised as one of the most effective MS organisations in the world, we continue providing world-beating service to Australians with MS and look for new and innovative ways to improve the day to day lives of people with MS.



"Everyone involved in MS research has a passion to be there on the day that a cure is announced. The formation of MS Research Australia under the aegis of MS Australia, represents a significant step forward in the Australian contribution for the achievement of that goal.

Research into a complex disease like MS must involve the brightest minds using a wide array of advanced technologies and scientific approaches. The co-ordination of the Australian MS research effort with the formation of MS national centres based on major research approaches, ensures the necessary co-ordination. Through this – synergy in the discovery of vital new knowledge – discoveries will lead to effective treatments in the future."

Graeme Stewart Director, Institute for Immunology & Allergy Research, Westmead Millennium Institute, The University of Sydney

#### The search for a cure

"Multiple Sclerosis Research Australia is an exciting initiative by MS Australia which has energised Australia's leading researchers and synergises the interface between the lay and research communities.

For the first time, laboratories and research groups in Australia's premier academic institutions have been brought together with a unifying identity and mission. Five major research centres have been formed, each focused on a key theme of MS research. Within the research centres are a total of 34 research laboratories and more than 150 scientists and clinical researchers. The coordinating role of MS Australia will also bring the challenge of MS research to the attention of Australia's corporate, scientific, government communities, and to the general public.

Often, the evening news advocates the stories of the world-leading achievements of Australian medical specialists in areas such as heart surgery, microsurgery, cancer research and MS research.

I always feel a great sense of pride in these local doctors and scientists, who seem to contribute disproportionately to global medical breakthroughs. The fact is, Australia has some of the most highly skilled researchers in the world."

#### Bill Carroll

Head, Department of Neurology, Sir Charles Gairdner Hospital, Perth, WA Chair, Medical Research and Advisory Board, MS Australia

#### We are at a real turning point.

MS Research Australia will deliver a new and outcome-driven approach to funding research. We believe that to solve any difficult problem we have to first ask the right questions. We believe that it is not just quality of expertise that counts; it is enablement, coordination and synergy that will leverage the outcomes we seek.

And in a world where linear thinking abounds, we will strive to empower lateral thought and exploit serendipity – how many of the greatest advances have come out of left field?

# Your investment can help make the next breakthrough for MS come from down-under.

MS Research Australia has a goal to raise \$30 million via a Capital Campaign over the next three years and will invest over \$3 million per annum over ten years. If an exciting potential breakthrough emerges we will add additional funds to accelerate the progress.

This will provide our world class Australian researchers with sustainable funding for direct research into finding a cure for Multiple Sclerosis.

#### To achieve this, we need partners like you who are willing to make an investment in this critical project....

In comparison to other relatively wealthy nations, Australia achieves a great deal with the limited resources available to us.

We will continue to find it difficult to retain the highest calibre medical research talent in Australia, due to the limited funding available. To rectify this, we must increase our investment in our best intellectual capital, while also promoting a highly productive approach to research.

We are committed to providing the most effective infrastructure for allocating funding to the areas in which it can have maximum impact in finding a cure for Multiple Sclerosis.

This is an exciting time in MS research. A time for us to make a significant push toward the cure for MS.

You have the opportunity to partner the Australian research team leading the way to finding a cure....

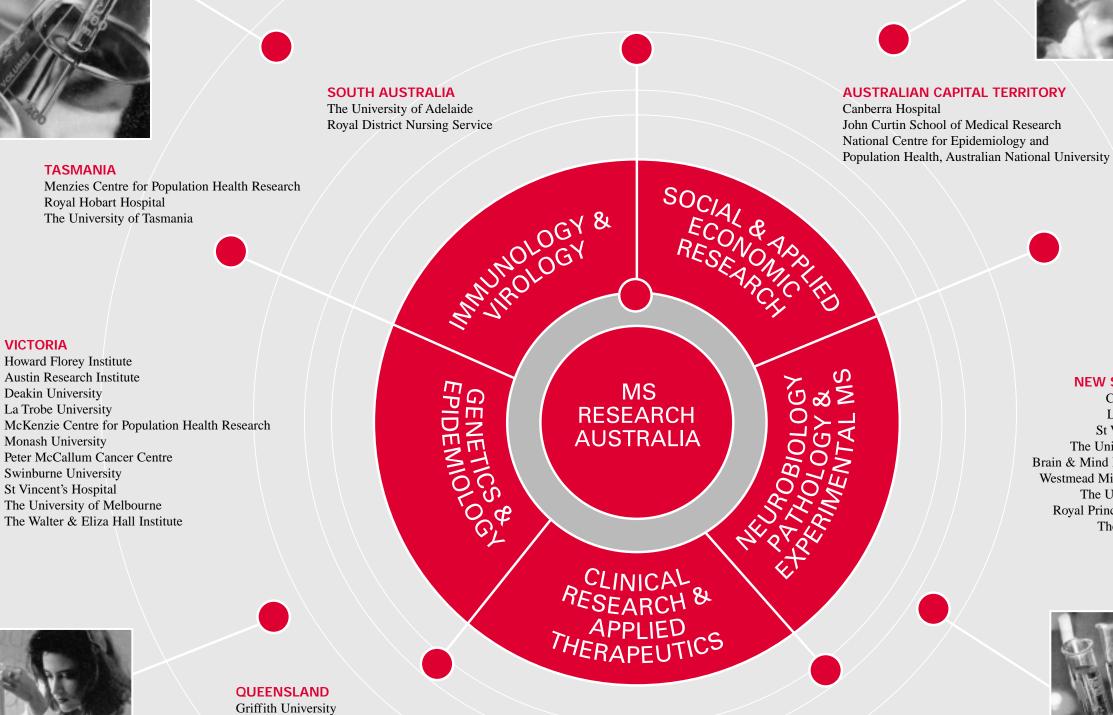
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> Australia is fortunate to have an internationally recognised clinical trial base





#### MS Research Australia: Five major research centres



Queensland Institute of Medical Research Queensland University of Technology The Queensland Brain Institute, The University of Queensland Neuroimmunology Research Centre, The University of Queensland Royal Brisbane and Womens Hospital James Cook University

#### WESTERN AUSTRALIA

Australian Neuromuscular Research Institute Queen Elizabeth II Medical Centre The University of Western Australia





#### **NEW SOUTH WALES**

**Centenary Institute** Liverpool Hospital St Vincent's Hospital The University of Sydney Brain & Mind Research Institute Westmead Millennium Institute The University of NSW Royal Prince Alfred Hospital The Garvan Institute



#### The research agenda

" **MS Research** Australia will lead the consolidated research effort, providing a direct partnership between the MS community and the research community

We are committed to maximising the value of every dollar invested in MS research in Australia.... Our goal is to move from an environment where researchers compete for funding, to one where there is substantial collaboration between disciplines to achieve results.

n order to fulfil our objectives and make this approach a reality, we have created MS Research Australia – a network of Australia's finest intellectual capital – a virtual research institute - with our best researchers who are committed to our approach to the future of Multiple Sclerosis research.

MS Research Australia will focus its research activity within the five major scientific disciplines, namely Immunology & Virology, Genetics & Epidemiology, Neurobiology, Clinical Research & Applied Therapeutics, and Social & Applied Economic Research.

The national approach aims to:

- eliminate the effects of MS by funding research into the causes, treatment, and management of the disease.
- take a thorough and strategic approach to research by focussing on promising areas, eliminating duplication with overseas researchers and improving accountability.
- apply the results of worldwide research towards programs of treatment, prevention and cure.
- encourage individuals and organisations to support a coordinated and nationwide research program.
- develop common systems to reduce costs, compare data and share resources.

MS Research Australia will focus its research activity within the five major scientific disciplines, namely Immunology, Genetics & Epidemioligy, Neurobiology, Clinical Research and Applied Therapeutics.

Using these disciplines, MS Research Australia is developing a research strategy which provides an immediate focus for funding large scale research on three central questions. These questions, if answered, will provide breakthroughs in understanding MS. The questions will relate to issues such as:

- Genetics, the Environment & MS
- Blood-Brain Barrier
- Myelin Repair and Regeneration

MS Research Australia will be supported by a committed volunteer network of senior advisors, who will establish and guide the governance and management processes.

This governance approach and structure will ensure that we implement the most proactive systems and strategies to deliver best practice research offering the greatest promise of alleviating the symptoms and finding the cure for Multiple Sclerosis.

We are committed to maximising the value of every dollar invested in MS research in Australia, by implementing a cost effective governance structure. This will direct funding into the areas of research most likely to make a significant impact on MS and will continue to measure researcher performance against pre-agreed goals and outcomes.

#### The research approach

MS research funding in Australia.

A Sustainable Research Environment

We have developed a sustainable framework for

funding, which encourages outstanding research

that offers the most promise of finding the cure

We are committed to communicating effectively

with government, the public and private sectors,

in Australia and drive increased funding into MS

We have developed a governance structure which will ensure effective and efficient management of the research effort and ensure research accountability. It will also ensure the highest standards of financial probity in the management

which will promote the profile of MS research

**Excellence in Governance** 

of funding granted for research.

for MS.

**Advocacy** 

research.

"I strongly support the establishment of a nationally coordinated research structure. MS Research Australia will act as a focus for both clinical and laboratory research, interacting with existing centres around Australia and raising the profile of MS research within Australia. It should be capable of attracting national and international funds and promoting collaborative projects.

In the area of clinical trials of new therapies, MS Research Australia will present a well organised national structure to pharmaceutical companies seeking to carry out multicentre trials. Such activities strengthen individual departments throughout Australia and serve to attract young neurologists and researchers into the field of MS. They also provide an opportunity for Australian patients to have access to the most up-to-date treatments."

John King Chairman, MS Subcommittee, Australian Association of Neurologists

Our approach will employ highly effective systems and structures for

#### Low Administrative Costs

The MS Societies will cover administrative costs from their contributions. In this way we will maximise the research investment.

#### Communication

We have a structured and robust communication process between our researchers, investors and donors, the MS Australia community, people with MS, and the broader community. This is essential to ensure that research is focused, relevant, and cost effective.

The outcome will be life-changing and life-saving for people with MS.

MS Research Australia will present a well organised national structure....

"The establishment of MS Research Australia will be very important in helping our research which involves immunological, virological, molecularbiology and genetic studies on MS aimed at understanding the cause of MS and ultimately leading to more effective treatments."

Michael Pender Professor of Medicine, The University of Queensland

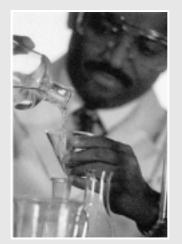








#### **Research governance and management**

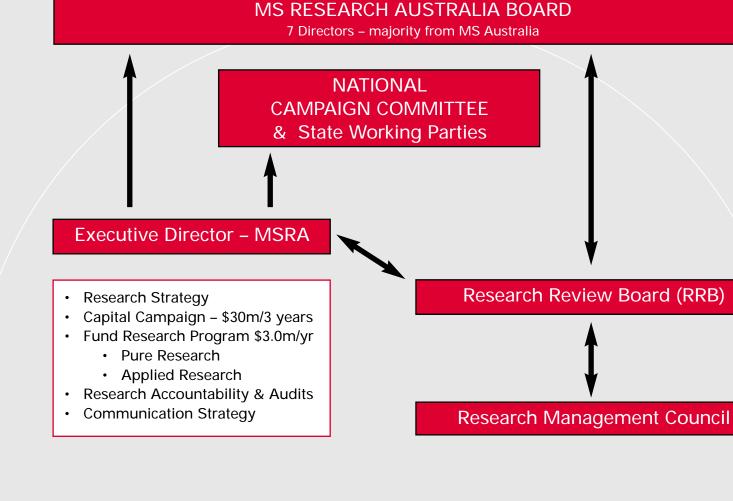


MS Research Australia; the entity which will manage and facilitate research activity and communication between researchers to ensure that we are achieving the best results for multiple sclerosis research. MS Research Australia will actively promote, develop, foster and support MS research activity in Australia in the pursuit of our objectives.

"My name is Jasmin. I am a 45 year old woman with a 13 year old son. Multiple Sclerosis has severely limited my working ability, at a time when my child's financial needs are ever increasing. A cure for MS, as a result of committed research, would enable me to properly provide for my child .... "

Jasmin Diagnosed age 28





MS RESEARCH AUSTRALIA – Governance Structure

#### **RESEARCH MANAGEMENT COUNCIL**

The Council is a multi-displinary group, which is responsible for managing the activities of the research initiative, including recommending grant allocations, monitoring and reviewing processes, and facilitating communication.



"MS Research Australia (MSRA) will promote a well co-ordinated, accountable, integrated and multi-disciplinary approach to MS research in Australia. The structure of MSRA will enhance communication among MS researchers within, and between, research groups. MSRA will also ensure that findings from research are communicated widely, so that they will make a difference to the lives of people with MS and their loved ones. A nationally co-ordinated research approach to MS will ensure that research funding is used efficiently and will move MS research forward in Australia."

Ken Pakenham

Director, Behaviour Research and Therapy Centre - School of Psychology The University of Queensland

#### NATIONAL CAMPAIGN COMMITTEE

The Capital Campaign Committee is responsible for raising \$30 million to enable sustainable funding of MS research in Australia.

#### **MS RESEARCH AUSTRALIA (MSRA)**

MSRA, with its DGR status, will be the recipient of funds and will in turn release funding of \$3million per year to research programs and projects, as directed by the MS Research Australia Board.

#### **MS RESEARCH AUSTRALIA** BOARD

The Committee holds overall responsibility for the development and ongoing management of the MS Australia research initiative. It receives direction and advice from the Research Review Board and provides direction for Research Grants.

#### **RESEARCH REVIEW BOARD** (RRB)

The RRB identifies promising areas of research and advises the strategic direction and focus for the allocation of funding for research, which will total over \$3 million per year. The RRB also monitors performance of the total research effort to ensure value for money spent and outcomes of the research effort. It meets infrequently and has international input.



#### Investing in the MS Breakthrough



"This is an exciting initiative that will help to place Australia at the cutting edge in solving the MS puzzle. MS Australia is to be congratulated for its insight and leadership in fostering and promoting MS Research Australia. I trust that corporate Australia will provide it with the support that it deserves."

Trevor Kilpatrick

Professor of Neurology, Centre for Neuroscience, The University of Melbourne Head, MS CARE Unit, Royal Melbourne Hospital Principal Research Fellow, Howard Florey Institute

#### ....an opportunity for MS Research Australia and researchers to leverage your funding with matching grants from government.



Direct medication, treatment & care – \$236m	
Nursing home costs – \$60m	
Informal care – \$99m	
Indirect cost of sickness, absence & early retirement – \$264m	

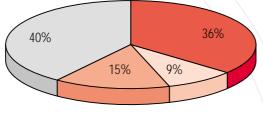
#### **Return on investment**

The return on your investment with MS Research Australia will be readily distinguished from your other investments, and well acknowledged..

Rather than investing in bricks and mortar, you will be enriching the future lives of people with MS by investing in our Australian research community and assisting them to find a cure for Multiple Sclerosis. Your investment may also provide an opportunity for MS Research Australia and researchers to leverage your funding with matching grants from government.

#### Economic Impact of MS

Behind the social cost of MS there is a measurable \*economic impact, totalling \$659 million per annum.



A breakthrough in MS research will have the direct effect of reducing this impact.

\*Economic Impact of MS Working Party, preliminary data, Australian MS Longitudinal Study, Rex Simmons – Project Manager, c/- Canberra Hospital, ACT, 2003-2004.

#### The Returns:

- You will be at the forefront of the search for the cure of Multiple Sclerosis.
- You will be acknowledged in medical and research fields and in the public arena as a leader in investing in neurological research.
- You will be recognised nationally and internationally as a leader in corporate social responsibility.
- You will be a patron to world class Australian research and research institutes.
- You will be providing hope and opportunity to people with MS, by assisting them to live full lives, make a contribution to society and to remain active in their personal and professional lives.

And when a cure is found, you will be part of the team that provided an essential ingredient in making it happen.



"If I could speak to my disease a decade ago, I would have been at its mercy.... If I could speak to my disease today – considering the fantastic and current promising research – I would say to it.... Be scared. Be very scared. We're coming at you.

But we're not coming from behind - we're coming from Down Under."

Trish Diagnosed age 29

#### **Committed to the MS Breakthrough**

#### **MS RESEARCH AUSTRALIA BOARD**



#### Simon McKeon (Chairman)

Simon McKeon is Executive Chairman of Macquarie Bank Limited's Melbourne office, President of the Federal Government's Australian Takeovers Panel and Chairman of the Point Nepean Community Trust. He is also on the Board of World Vision Australia and the Strategic Advisory Board of the University of Melbourne's Faculty of Law Graduate Programme.



#### Terry Winters (Deputy Chairman) Terry is Chairman of Multiple Sclerosis

Society of Victoria Ltd, Opportunity International Australia Ltd, Netcomm Ltd and Protocom Development Systems Pty Ltd. He is also a director of Commander Communications Ltd and Multiple Sclerosis Australia Ltd.



## Bill Carroll

Dr Carroll is currently Head, Neurology Dept, Sir Charles Gairdner Hospital, Perth, Western Australia, Chair, MSA Medical and Research Advisory Board, past President, Australian Association of Neurologists and a Trustee, World Federation of Neurology.



#### Chris Gillies

Chris Gillies is a Non Executive Director focusing on IT Governance in the boardroom and an independent Consultant, specialising in implementing large change programs in both the public and private sectors.

#### Graham Tribe

Graham has had a 34 year career in engineering, then marketing and manufacturing. He headed the Australian and Asia Pacific business for both Hyster and Yale brands.

Graham is currently President of MS Australia.



#### Graeme Stewart AM

Graeme is a clinical Immunologist with 25 years of involvement in MS research in the areas of genetics and immunology. He is the Director of the Institute for Immunology and Allergy research on the Westmead Campus of The University of Sydney.



#### Gabrielle Dalmau

Gabrielle Dalmau has been working with MS Australia on a voluntary and consulting basis for the past few years to assist the Societies' CEOs in formulating the national strategy for MSA, and Research is at the centre of this strategy. She has a background in Human Resources, Change and Business Management working across the public and corporate sectors.





#### Professor Jim McLeod AO

Jim McLeod is a neurologist and Emeritus Professor at the University of Sydney. He has been involved in MS research for over 30 years. He was a member of the Research Advisory Board of NMSSA and MS Australia for 20 years and was Chairman 1996-9.

#### **EXECUTIVE DIRECTOR**



#### Jeremy Wright

Jeremy has many years of senior business and marketing experience with companies including Ogilvy & Mather, Optus, and Energy Australia. He was previously President of the Sudden Infant Death Association and has served on boards including Sydney Dance Company, Telstra ChildFlight and the Starlight Foundation.



MS Australia The Studdy MS Centre Joseph Street (PO Box 210) Lidcombe NSW 2141 Website: www.msnsw.org.au

**MS** Australia

The Nerve Centre 54 Railway Road (Private Bag 900) Blackburn Victoria 3130 Website: www.msaustralia.org.au/vic



MS Research Australia Phillips MS Centre 293 Mowbray Road Chatswood NSW 2067 Website: www.msaustralia.org.au

Freecall 1800 287 367

Acknowledgments: Trish MS Research Foundation Ph: 0410 410 491 www.trishmsresearch.org.au Alister Heighway Design Ph: 0419 274 728 Bug Media Ph: 02 9871 4139 / 0425 294 746

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