



THE OFFICIAL NEWSLETTER OF MULTIPLE SCLEROSIS RESEARCH AUSTRALIA – THE RESEARCH ARM OF MS AUSTRALIA

New report documents financial burden of MS

The fact that MS has a significant financial impact on individuals and families will come as no surprise to those living with the condition. Now a report commissioned by MSRA has fully documented the costs of MS to the individual and the Australian community as a whole.

The Economic Impact of Multiple Sclerosis in 2010 report, was conducted by health economists at Covance together with the Menzies Research Institute Tasmania. The report, launched in November, provides a much needed update to the only previous evaluation of the costs of MS conducted in 2005 by Access Economics.

Prof Andrew Palmer, Head of Health Economics at the Menzies Institute, acknowledges that this report highlights important trends which should be addressed. For example, the current prevalence of MS in Australia, medication and caring costs and importantly the loss of employment.

MS now affects over 21,000 Australians, 75% of whom are women, and costs a total of \$1.04 billion per year. This is an increase of \$380 million since last evaluated in 2005.

'In some respects our findings were as expected,' said Prof Palmer. 'Medication is a major part of the direct costs,

however, as the disease increases in severity these costs are far outweighed by lost productivity.'

'This suggests a cost-effective approach for the future is to focus on prevention and improved treatments. If these can slow or halt the progression of disability, the burden to families and the economy as a whole will be greatly reduced.'

As Jeremy Wright, Executive Director of MSRA adds, 'fully supporting people with MS with their specific needs in relation to disability and chronic illness is crucial. This report supports the development of a national disability insurance scheme. It also emphasises the need for investment in research and the need to do everything we can to prevent MS. A clinical trial of the preventative benefits of vitamin D, for example, is now being rolled out, but requires further funding.'

'It is also clear from this report that there is a great need for investment in resources, services and environments that will assist people with MS to remain in employment.'

The full report can be viewed on our website www.msra.org.au.

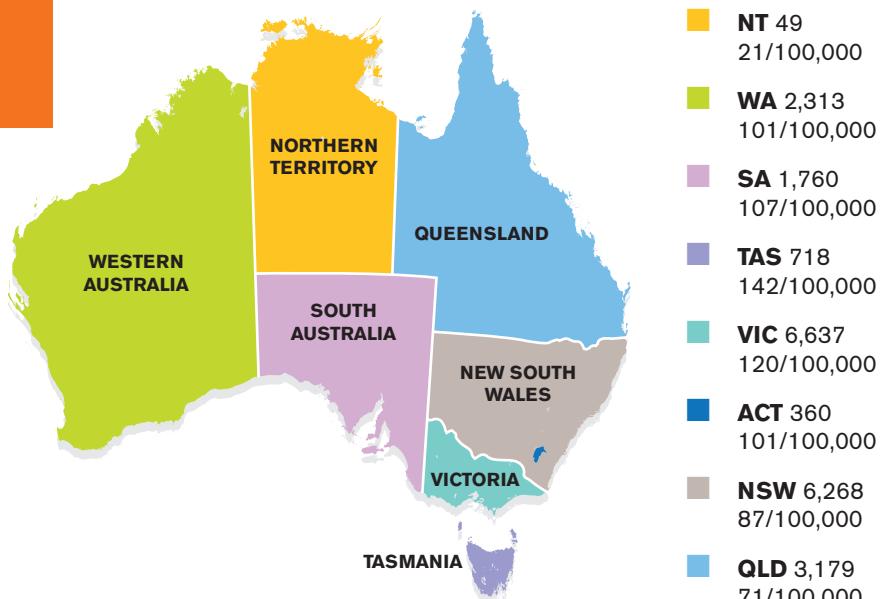
Production of the report was supported by the Macquarie Group Foundation. ■

Prevalence of Multiple Sclerosis

Australia Total

21,283
96/100,000

(MS cases per 100,000)



Sharing progress in MS research



FROM LEFT TO RIGHT: PROF SIMON BROADLEY, GRIFFITH UNIVERSITY QLD, YOUNG INVESTIGATOR WINNER NANCY MOXEY, UNIVERSITY OF QUEENSLAND, A/PROF SERGIO BARANZINI, UNIVERSITY OF CALIFORNIA SAN FRANCISCO AND PROF GIANVITO MARTINO, SAN RAFAELLE UNIVERSITY ITALY WITH DR JUN YAN, UNIVERSITY OF QUEENSLAND.

MSRA's 2011 *Progress in MS Research* conference, which took place in Melbourne, in October, was infused with excitement, hope and a very real sense of achievement.

It attracted leading researchers from around Australia and the globe and covered every field of MS research including pathology, experimental therapeutics, clinical and applied research, genetics, epidemiology, stem cells and immune tolerance.

MSRA Research Chairman, Prof Bill Carroll, welcomed delegates and gave an overview of recent advances, including the genetics of MS and the pipeline of new therapies currently in trials. He applauded the Australian MS research community for their enormous contribution to this global progress.

Leading international researchers shared their expertise and results. Dr Bruce Trapp, Lerner Research Institute, presented work on the earliest damage to the grey matter in MS, invisible by MRI, but a significant contributor to symptoms. A/Prof Betty Soliven, University of Chicago, discussed her work on the brain and immune system molecule, S1P receptor, as a target for treatment. A/Prof Sergio Baranzini from University of California San Francisco, shared his studies on the genetics and epigenetics (changes in gene activity) of twin pairs and rare familial cases of MS. Prof Gianvito Martino talked about the current status of research into stem cell therapies for MS, including bone marrow transplantation,

and the promising experimental results for neural, mesenchymal and induced pluripotent stem cells.

There was a notable increase in the number of young scientists attending. Young Investigator Awards went to Nancy Moxey, University of Queensland, for her poster on the role of rare mutations in myelin proteins; and to Steve Simpson Jr Menzies Research Institute Tasmania, for his podium presentation on the influence of interferon-beta and blood levels of vitamin D on relapse risk in MS.

In a final session, key Australian researchers gave their views on where to next. Prof Graeme Stewart presented a road-map suggested by the recent genetic discoveries; Prof Helmut Butzkueven outlined the imminent launch of the vitamin D prevention trial; Dr Mark Slee discussed developments in diagnosing the MS-sister disease, neuromyelitis optica (NMO); and Dr John Parratt reviewed the clues to the origin of MS revealed by studying the earliest signs of pathology in MS brain tissue. Prof Trevor Kilpatrick drew together the threads of the many different areas of MS research and developments in technology that will see us make further progress in the near future.

The conference received media interest and was accompanied by a well-attended public lecture for people with MS and their families. MSRA is proud to have supported a very large proportion of this exciting progress in MS research and looks forward to seeing the rewards of the increased numbers of bright young scientists who are now working to improve our understanding of the disease. ■

Gals with H'art

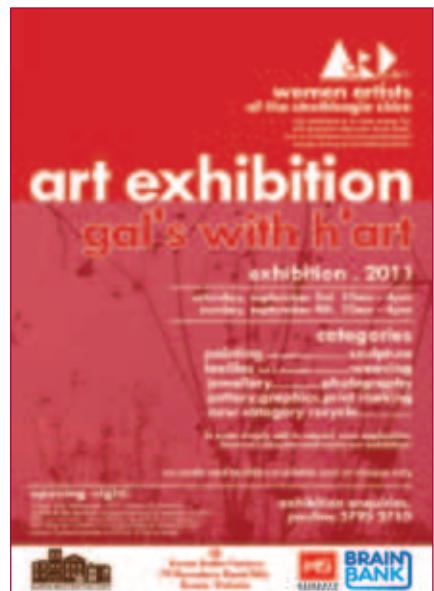
The Gals with H'art art exhibition is an annual event dedicated to raising funds for the MSRA Brain Bank.

The brainchild of Louise-Anne Lewin, a woman with MS based in Euroa, Gals with H'art took place on the 3rd and 4th of September this year at the Euroa Butter Factory and raised over \$2,000 for the MSRA Brain Bank.

Some 23 artists submitted over 90 pieces of art for this year's exhibition. The range of works was extensive comprising of pottery, textiles, painting, sculpture, jewellery, weaving and photography. A percentage of exhibit sales contributed to the funds raised as did a raffle of items generously donated by local businesses. ■



■ THE GALS WITH H'ART TEAM.



Include A Charity

MSRA is proud to be a member of the new 'Include A Charity' initiative in Australia. Drawing on a highly successful campaign in the UK, it is designed to raise awareness of the ease and effectiveness of donating to charity in your will. It encourages people to consider leaving a bequest after considering gifts to family and friends.

'Include A Charity' is the result of over 130 of Australia's favourite charities working together to do what no single charity might easily achieve on its own – change the way Australians think about making a difference; made possible in a will.

Leaving something to charities is not the province of only the wealthy. People from all walks of life like to feel

their hard-earned funds might also contribute to a better world after they are gone. Even a modest gift could be life changing for certain people in a community.

Bequests left in wills are important to many of Australia's well-loved charities. Without these gifts a number of them would struggle to survive. While Australia and New Zealand are reported to be the most generous* countries in the world, only 7.5%* of Australians aged 60 and over actually choose to include a gift to a charity in their will, although that is beginning to change.

'Include A Charity' aims to help people understand the value of a gift to benefit society as well as remembering their loved ones. It is a lasting legacy shared by all Australians.

For more information on leaving a gift in your will to MS research, please visit www.msra.org.au/bequests or fill in the form and tick the request box on the back page of this newsletter.

For more details on Include A Charity, please visit www.includeacharity.com.au.

*World Giving Index 2010 Report issued by the Charities Aid Foundation, an international not-for-profit organisation. ■

The screenshot shows the 'include a charity' website with a red header. The main banner features a blue sign that reads 'polio, smallpox, leprosy' with a crossed-out 'multiple sclerosis' below it, followed by 'Help us cross it off too'. Below the banner are four links: 'Why leave a gift in your will?', 'How to leave a gift in your will', 'Find a charity', and 'View our TV commercial'. At the bottom, there is a link to 'Leave your legacy' with a brief description of the process.

include a charity
Help the work live on.

Brain bank earns 7% interest !



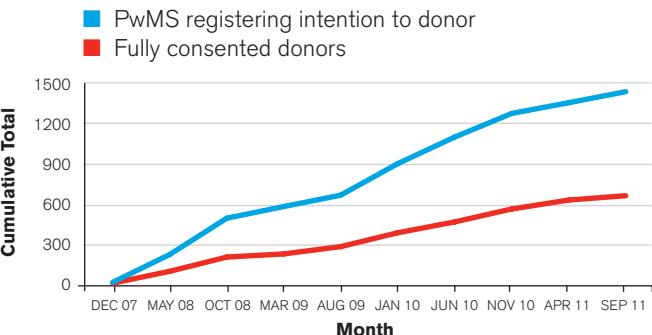
As we go to press MSRA is pleased to report that already 656 Australians with MS have consented to become brain donors in the future. A further 900 people have registered their interest and received consent packs.

The total of 1,556 represents an incredible 7% of the approximate 21,000 People with MS (PwMS) in Australia. This demonstrates the determination of PwMS to contribute to finding a cure. We need to continue to register donors so that MS researchers can conduct ground-breaking research to find the cause and a cure for MS.

Having an MS specific brain bank allows MSRA to stimulate MS research here in Australia. In the UK, the MS Brain Bank has brought outstanding growth in the research being conducted. There has been a trajectory in scientific studies using donated brain tissue and over 175 scientific publications resulting from generous brain tissue donations received since establishment in 1998. If we can follow their lead, the future is bright at the brain bank.

If you wish to register as a brain and tissue donor please phone 1300 672 265, email msrabrainbank@msra.org.au or register online at www.msbrainbank.org.au to receive your consent pack. ■

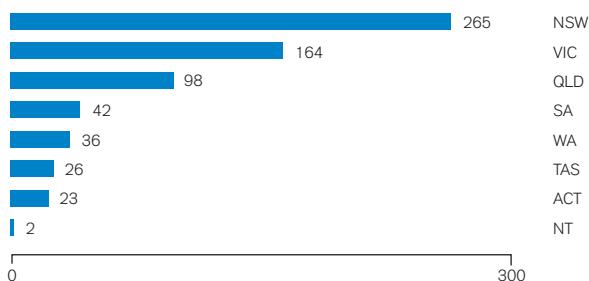
MSRA Brain Bank



MSRA Brain Bank

Fully Consented Donors by State

Score from 0 – 300



Trial results for emerging MS therapies

The largest international annual conference on basic and clinical research in MS was held in Amsterdam recently by the European Committee for Treatment and Research in MS (ECTRIMS). Results of several clinical trials of new therapies were presented which suggest a promising future for further MS treatments.

New oral drug BG-12 has shown surprisingly good efficacy in the recently completed phase III trial. This drug belongs to a class of compounds known as fumarates, which act by a different biological pathway to currently available MS drugs. It modifies the immune system, but there is some evidence that it may also have neuroprotective effects. BG-12 showed at least a 50% reduction in relapses and 38% reduction in disability progression with very significant reductions in lesions visible by MRI. These benefits appear to be in line with some of the MS treatments already approved for use, and with a favourable safety profile, it is also likely that BG-12 may be used in combination with existing treatments.

Alemtuzumab is a monoclonal antibody, currently used for the treatment of some types of leukaemia. Results of the five year follow-up of the trials of Alemtuzumab in MS showed it was more effective than interferon-beta in reducing relapse rates in early aggressive cases of MS and it also showed a

sustained effect in improving disability. That being said, some significant side-effects can occur such as opportunistic infections and secondary-autoimmune thyroiditis.

Phase III trial results for the oral drug Teriflunomide have previously been released to the public, but have now been published in the peer-reviewed *New England Journal of Medicine*. The results show that the efficacy of Teriflunomide in reducing relapses and MRI-visible lesions appears to be similar to the interferons. The side-effect profile is also reasonable with no significant increase in opportunistic infections.

It will still be some time before these new therapies can pass through the regulatory frameworks for new medicines, but the landscape for MS treatment is set to change with greatly increased options for people with MS in the near future.

For more information on the clinical trials process or MS clinical trials currently in progress in Australia please visit www.mstrial.org.au ■





Run for love

In this year's annual Sydney City 2 Surf, Foundation 5 Million Plus (F5m+) had two very driven and inspiring runners in our team.

The City 2 Surf has always been an activity enjoyed by the Hill family, especially Laura, 27. So it was only natural that when Laura's mother Elizabeth was diagnosed with MS in 2006, that Laura would take steps to run for MS research. For the past two years she was awarded the F5m+ top individual fundraiser raising just over \$3,000 and this year she more than trebled her incredible efforts, collecting over \$10,000.

As a first time fundraiser for F5m+, Craig White joined our team this year in memory of his dad, a man who had a severe type of MS which sadly took him at the age of 42. Craig raised an impressive \$7,830 for MS research. 'It is my small way of creating hope for those with MS' he said.

As anyone who has ever taken part in raising funds for charity understands, in order to achieve such wonderful results there are many people behind the scenes who deserve to be thanked. Both Laura and Craig would like to thank their family and friends as well as all of their wonderful supporters at work and in their communities. ■



RUNNERS CRAIG WHITE AND LAURA HILL WITH F5M+ MANAGER, NEIL ROBERTSON AT THE CITY2SURF.

One Man. Two Wheels. 2,500Km.

In March 2012 one man will set out on two wheels to three major cities and cycle nearly 2,500 kilometres of bitumen and coastline.

Sean Sampson will do this amazing Brisbane to Melbourne (B2M) feat for two excellent causes. The first is us! He chose Foundation 5 Million Plus as he was inspired by the late Ian Ballard, the founder of this great initiative. His other charity is Cottage by the Sea. We wish him safe travels AND we urge everyone to log on and make it worth his while to undertake this altruistic event or join him on his journey www.brisbane2melbourne.com ■



SEAN SAMPSON TRAINS FOR THE B2M EVENT.

brisbane 
melbourne
www.brisbane2melbourne.com march 2012

Throw the Book at MS

Organisers for events in Brisbane, Mosman and Paddington as well as numerous book groups around the country have reported a fantastic result of over \$27,000 in 2011 and a five year total of \$87,402 for MS research.

The theme of these trivia nights is books and authors, so anyone looking for a ready-made event to run in your own suburb or town can contact register@throwthebookatms.org.au. You will be supplied with questions (and answers for organisers) and easy tips for fundraising. ■

Set sail and kiss goodbye to MS!

Get up early this Boxing Day morning for the Sydney to Hobart Yacht Race. Watching on TV or from the shore, you will see that seasoned Melbourne ocean racer, Beyond Outrageous, has been rebranded as the Kiss Goodbye to MS yacht for the 2011 event.

MSRA is thrilled that the crew from Beyond Outrageous, based at the Royal Melbourne Yacht Squadron, has chosen to raise awareness of MS at this world famous event. Crew member and person with MS, Dr Ian Law says, 'I'm extremely excited to be competing in the 2011 Sydney to Hobart Yacht Race. This is a great way to raise awareness of MS and a fantastic precursor to the 2012 Kiss Goodbye to MS campaign which will take place throughout May next year.' Tony Warren, owner and skipper, of Kiss Goodbye to MS, is a seasoned ocean racer having raced the two-handed 5500 nautical mile Melbourne to Osaka race three times and has competed in the Sydney to Hobart three times.

In an added bonus for the Sydney to Hobart Kiss Goodbye to MS Team, Simon McKeon – Australian of the Year and founding Chairman of MS Research Australia – is



the Patron for their sailing adventure. Not only is Mr McKeon a lawyer, investment banker, philanthropist and person with MS – he is also the holder of a world speed sailing record!

More details on the 2012 Kiss Goodbye to MS Campaign will be available from the MSRA website in early 2012 and further information will be included in our March newsletter.

To support the crew with their fundraising for MS research please donate at www.everydayhero.com.au/event/KissGoodbye2MS_Sydney2Hobart2011

MSRA Partners



Blake Dawson



Australian Government
Department of Health and Ageing



Yes, I want to help MS Research Australia

Mail this form or donate online www.msra.org.au Donations over \$2 are tax deductible

- My one off tax deductible donation is \$ _____
 I want to support MSRA on an ongoing basis.
please charge \$ _____ to my credit card per month until notified.
 Please debit my: Visa Card Mastercard Amex
Card No: _____
Exp: _____ / _____ Signature: _____
 OR I have enclosed my: Cheque/Money Order payable to MS Research Australia.

Title: _____ First Name: _____ Surname: _____
Address: _____
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Telephone (W): _____ (H): _____
Email: _____

- Please note here if your donation is made in memory of someone or for a function.
name of person / function name: _____

- Please send me information on how I may support MSRA in my Will.
 Check this box if you do not wish to receive future updates from MSRA



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