



## The Parliament, the people, the passion

**Dr John Richert, Vice President of the American National MS Society (NMSS) and John Coombs, former National Secretary of the Maritime Union of Australia, made a personal plea in March to the Australian Government for increased research funding for MS.**

MSRA has itself thrown down the gauntlet to government, stating that if it will make \$5 million available in the budget for MS research, MSRA will match the amount, dollar for dollar, with private sponsorship.

On 17 March MSRA & the National Health and Medical Research Council (NHMRC) co-hosted a parliamentary breakfast briefing on the prevention of MS. Over 80 politicians and their advisors attended the presentation at Parliament House, Canberra, an outstanding attendance – three times the usual number!

They were there to be briefed about MS from a passionate group of speakers, headed up by visiting American MS research expert, Dr John Richert.

A strong advocate for the quality of science conducted by Australian MS researchers, Dr Richert has put his money where his mouth is. His organisation, the NMSS, invests \$1 million p.a. in Australian researchers because they continue to get results. His American donors don't mind that he directs some of their funds to another country; they just want the cure to be found, wherever that might be.



▶ **JOHN COOMBS, WITH A PHOTO OF HIS SON GARRY WHO SADLY DIED ON 1 MAY.**

Other key note speakers included Senator Kate Lundy who spoke on behalf of the Parliamentary Friends of MS group, Senator Jan McLucas, the Parliamentary Secretary for Health and Ageing who spoke on behalf of the Prime Minister, and Natalie Walsh, an MSA advocate, who spoke on behalf of people with MS.

However, it was John Coombs who reached the audience with his emotional speech. His family has been affected by the disease and he was able to highlight the human face of MS and the importance of developing a prevention program.

To view video clips of the presentations and the media coverage received, including a feature on the ABC's 7:30 Report, visit [www.msra.org.au](http://www.msra.org.au)

## Triple reasons - triple the reward

### A cure for MS: What does that mean?

Well, it means different things to different people.

For those with MS at the early disease stage who have not yet sustained a significant amount of disability, a cure would be to stop the destructive process in the nervous system.

For someone who is already struggling with MS-induced disabilities, a cure would be to repair the nervous system, and reverse their neurologic disability.

And for people who are worried about their children or grandchildren developing MS, a cure would be to prevent the disease from occurring in the first place.



▶ **PARLIAMENTARY BREAKFAST KEYNOTE SPEAKERS**  
L TO R: SENATOR JAN McLUCAS, JOHN COOMBS, NATALIE WALSH, DR BILL CARROLL, SENATOR KATE LUNDY, DR JOHN RICHERT AND PROF WARWICK ANDERSON.

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## Triple reasons – triple the reward

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For MS researchers, this means triple the complexity and triple the cost compared with tackling only a single cure.

That's the key message delivered by Dr John Richert, Vice-President of Clinical Programs and Research at the US National MS Society (NMSS) during his whirlwind visit to Australia. He and his wife, Dr Nancy Richert (a scientist developing tools to measure the effect of neuroprotective treatments), attended 36 meetings in 10 days and met with over 400 people from around Australia!

The NMSS is the largest private funding body of MS research in the world spending over US\$40 million annually. Among Australian projects, it has supported the Ausimmune study with AU\$1 million to investigate the environmental triggers of MS.

During his visit, Dr Richert talked about other NMSS funded work, such as the *Fast Forward* program, which injects funding to accelerate new treatments into MS clinical trials.

It was also a unique opportunity for people with MS and *MSRA Research Partners* to speak with two researchers at the forefront of their fields.

The NMSS sets a gold standard in governance. Each project funded by NMSS is scrutinised by international assessors then reviewed by experts who ensure that only the



► DR WILLIAM CARROLL (CHAIRMAN OF MSRA RESEARCH MANAGEMENT COUNCIL) AND DR JOHN RICHERT.

best research in MS is funded. This is akin to MSRA's rigorous peer review process via the Research Management Council. Donors to either organisation can have confidence that a merit-based system is in place to ensure their donation is well-spent.

MSRA is forging collaborations with MS Societies internationally. Our relationship with the UK MS Society continues to grow (see below). MSRA invited Drs John and Nancy Richert to help forge a stronger link with the NMSS.

## Why MS research? Because there is so much hope!



**The first person to be awarded the Macquarie Group Foundation MSRA/UK MS Society Fellowship, Dr Julia Morahan, is making the move from research in Motor Neurone Disease (MND) to MS.**

What attracts her to MS is that there is real hope for a cure in the near future.

'We are close to getting definite answers and close to a treatment option. We will be able to achieve

actual positive outcomes in the lives of those with MS,' says Dr Morahan.

Dr Morahan will undertake the three-year post doctoral study in the Oxford laboratory of Professor George Ebers, a leader in MS research. She will be researching the genetic predisposition to the disease.

'It was originally thought that one particular gene was implicated in MS but potentially three or four genes are involved. I'll be looking at isolating those genes.

'The area of the genome where these genes are found is so complex. It controls what makes people's cells unique,' says Dr Morahan.

She'll be fine mapping the area, teasing out her target genes from what is essentially the most complex part of the genome. This observation of the differences regarding the genetic sequence is a more traditional research approach, and Dr Morahan will also pursue another research tack: looking at how genes get silenced.

'There's a process called methylation which is the 'turning off' and 'turning on' of genes. Things bind to the DNA and stop the switching mechanism, so the gene remains switched on when it should be switched off.'

Jeremy Wright, Executive Director of MS Research Australia, adds: 'As a young scientist in the area of neuroscience, Dr Morahan has already added to the understanding of MND. I am delighted that she is using her scientific prowess to help people with MS.'

'The Fellowship furthers MSRA's aim of creating international links to take advantage of research strengths in other countries. It also provides the opportunity to train Australian scientists in cutting-edge technology. We are indebted to the Macquarie Group Foundation which has been instrumental in getting this Fellowship established.'

## Ordinary to Extraordinary Man

**A celebration of the life of Ian Ballard will be held on 3 July at the Sydney Hilton Hotel. The founder of F5m has been an inspiration to all in the MS community.**

Ian was optimistic and passionate about what people with MS could do to find a cure. It is only fitting that this event in his honour will be a joyous celebration. MC for the night will be James Mathieson, past presenter of Australian Idol. James, one of Ian's ex-colleagues from XYZnetworks, was on hand to help with the breakfast launch of F5m in 2005.

Diageo is one of the many corporate supporters for the event. To buy a ticket and be a part of this extraordinary night of celebrations call 1300 356 467 or visit [www.F5m.org.au](http://www.F5m.org.au)



▶ EXTRAORDINARY MAN, IAN BALLARD.

## Barging through Europe for a cure

**Stewart and Lesley MacLennan have set themselves a mighty challenge.**

They have built a barge which is more than 17 metres long and weighs over 37 tons in which they aim to cover over 1,500kms and negotiate more than 200 locks in three countries, all in just 100 days. 'Endellion' is no ordinary vessel. With a hydraulic platform to lift Stewart in his power wheelchair from the living level to the lever-based steering system, the barge has been tailor-made to meet Stewart's needs. Through the journey from London to Laroche in Burgundy, France, Stewart will be pursuing his dream trip whilst raising funds for F5m and MS research. Visit his Everyday Hero website to show your support:

[www.everydayhero.com.au/stewart\\_maclellan](http://www.everydayhero.com.au/stewart_maclellan)



▶ STUART AND LESLEY'S BARGE 'ENDELLION'.

## Book of bargains

**The Entertainment Book is a great way to get bargains in dining, entertainment and accommodation.**

You can now purchase the book and make sure that the proceeds go to F5m. A Vodafone employee Fionna Guy, along with Valentino Surjan, have set up a website to sell the books, with proceeds directly supporting F5m & MS research. As an added bonus, Vodafone will match the amount donated up to \$3,000. Visit [www.F5m.org.au](http://www.F5m.org.au) for more details.

## Calling all runners!

**If you plan to participate in a large or small sporting event this year, consider raising funds for F5m & MS research while you train up for the day.**

The Everyday Hero website allows you to set up a fundraising page, allowing your friends and colleagues to show their support for you and your cause. No need to wander the office collecting money or issuing receipts. The website does it all for you! Just send a group email to all your buddies letting them know you'll be running (cycling, walking, swimming . . .) and provide a link to your page on the Everyday Hero website. With the Run Melbourne and City to Surf coming up, here's your chance to attain your personal best and help others . . . all in the one stride.

## Coming up

**Art for MS** – *Waiting – A Still Life* is the title of an art exhibition being run for F5m at the NG Art Gallery. The theme of waiting relates to people with MS, claims the gallery, as they wait in hope for research to provide relief. The exhibition runs from 30 June to 25 July.

During the exhibition the gallery will host two 'Feast for the Senses' dinners – on 7 and 26 July at 3 Little Queen St, Chippendale. More info at [www.ngart.com.au](http://www.ngart.com.au) or call (02) 9318 2992.

**Throw the Book** – Last year 60 book clubs around Australia took part. What will it be this year? Send off for the questions to run your own at [throw.the.book@hotmail.com](mailto:throw.the.book@hotmail.com) or attend one of the larger events in Sydney, at Mosman (3 June), Chatswood (14 June) or Paddington (18 June). For more details visit <http://www.F5m.org.au/F5m-throw-the-book.html>

**Latin Rhythms** – Those who attended the Latin Rhythms event at Club Marconi on 28 March had a taste of what's to come when the main event kicks off on 8 August. Don't miss the big night when Bolivian dancers will be strutting their stuff, along with other South American performers and bands. So you think you can dance? Come and show us! Call (02) 9822 3333 or email: [mrlatinspectacular@hotmail.com](mailto:mrlatinspectacular@hotmail.com)

# Information is power!

## MuSt be an Angel

**Mixing business with charity is what MS Angels do best. The Angels – a group of Sydney-based female business leaders – was formed last year to support MS research while building stronger professional networks.**

'We have a dual purpose,' says Victoria Weekes, one of the group of 20 women invited to join up. 'The Angels are not just about raising money for an important cause. What's different about us, is giving as a group to support a piece of research that's important to us as well as getting to know and support each other in our career objectives.'

The MS Angels have collectively decided to support Laura Gianni, a young PhD scholarship recipient studying proteomics at University of Melbourne, Bio21 Institute.

MS is a disease that commonly affects women at the early and middle stages of their careers. It is, therefore, a cause that warrants the attention of well-connected women; both in the support of research and the raising of awareness among their colleagues, friends and families.

MSRA hopes to launch MS Angels chapters in Melbourne, Canberra and Brisbane in 2010 and 2011.



► RESEARCHER  
LAURA GIANNI.

**Eye specialist Dr Celia Chen believes that information is power. But she also thinks that you can get 'bogged down' in too much information.**

Dr Chen has just been awarded the National Institute of Clinical Studies (NICS) – MSRA Fellowship.

Her two years of research will focus on the doctor/client partnership model of health management. She believes that both have to take a shared responsibility for optimal results.

'Patients like to be informed but they don't always know where to get the best information. They very frequently arrive with 100s of pages they have downloaded from the internet, saying they want this therapy when it may not be the best for them,' says Dr Chen.

NICS is an institute of the National Health and Medical Research Council. For more information visit [www.msra.org.au](http://www.msra.org.au)



► DR CELIA CHEN.

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### MSRA Partners



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My tax deductible donation is \$ \_\_\_\_\_

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OR I have enclosed my: Cheque/Money Order payable to MS Research Australia.

I want to support MS Research Australia on an ongoing basis, please charge \$ \_\_\_\_\_ to my credit card per month until notified.



**To donate now go to [www.msra.org.au](http://www.msra.org.au)**

**Donations over \$2 are tax deductible**

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