

THE OFFICIAL NEWSLETTER OF MULTIPLE SCLEROSIS RESEARCH AUSTRALIA

MS Awareness Week 4-10 June 2006 MS Awareness Week 4-10 June 2006 MS Awareness Week 4-10 June 2006 MS Awareness Week 4-10 June 2006

Planning a national patient register for clinical trials

Multiple Sclerosis Research Australia (MSRA) is exploring a new way to co-ordinate clinical trials on behalf of Australians with MS.

At a round table discussion in March with medical leaders from around the country, new ideas were debated on how best to coordinate clinical research efforts and make findings available for public scrutiny.

At the moment efforts to embark on new ways of researching and approaching clinical trials are sometimes delayed because of issues relating to current ethics committees.

According to Assoc Professor Rob Heard from the University of Sydney (Westmead Campus), the first step to addressing these issues is for MSRA to establish a national patient registry. He believes that if every person with MS is registered, then future research subjects can be easily identified and contacted.

The next step is to register all MS clinical trials on a specific online database. The proposed MSRA National Clinical Trials Register could be available to the public, and all research done in Australia would be logged on a purpose-built website.

In conjunction with these new ideas are thoughts to set up a centralised MS Ethics Committee which can approve studies more quickly and efficiently than the current system.

According to Professor Heard, MSRA could provide this restructure to those with the disease and believes the model could eventually become a benchmark for other diseases.

MSRA invited two groups to present their experiences to the conference. The Australasian Stroke Trials Network via Dr Denis Crimmins indicated that their success in attracting new research was due to their implementation of a centralised system which allowed for more accurate reviewing of trials.



▶ ASSOC. PROFESSOR ROB HEARD

However, the ex Chair of the Aust/NZ Thoracic Society's ethics committee, Dr Chris Clarke, warned MSRA to be cautious. His experience with establishing an ethics committee proved to be difficult, and after only a few years the committee had to be disbanded.

MSRA hopes to learn from these two examples and find the best way to use information for a sole purpose – to better treat those with MS.

Weather man... iron man... Super man!

Graham Creed, the Weather Channel's weather man, doubles as an Iron Man in his spare time.

Competing in this year's Iron Man Triathlon, Graham collected pledges before the event to raise money for MS.

This is the second time he has taken part and he set himself the challenge of completing the gruelling course in under 10hrs, hoping that donors would double their pledges if he achieved that goal. He managed to finish in just a little over that time – crossing the line in 10 and a half hours, even then an amazing feat!

Raising \$3,500 in pledges now makes him something of a Super Man as well.



▶ FRIDAY 9 JUNE. GIVE US A HAND... OR A WRIST.

On Friday 9 June – give F5m a hand... or your wrist!

Families and friends of people with MS and lots of school kids and supporters – will be selling purple and green wristbands in Sydney and Melbourne, at CBD train stations and elsewhere around the metro area.

Look out for the F5m team on Friday June 9, during MS Awareness Week around Australia. All proceeds go to MSRA for on-going research programs. If you want sell wristbands contact F5m on 1300 356 567 or info@F5m.org.au



▶ GRAHAM CREED IN ACTION.

Photo with thanks James @ triathlonPhotos.com

But How Are You... Really?

Whether it's because they don't want to be seen as whingers, or because they believe there are others worse off than themselves, some Australians with MS are apparently hiding the full impact of their MS from their doctors. That's some surprising preliminary data from the *Australian MS Longitudinal Study* (AMSLS; also known as the MS Life Study.) The study uses self-reporting surveys that need to be validated and it was during this validation process that a discrepancy was found between what people said about their MS in an anonymous survey, and what their doctors said independently using the same disability scale.

'At the more severe levels of disability, where immobility and other difficulties cannot be hidden, doctors and patients will make similar assessments,' says Project Manager for the AMSLS, Dr Rex Simmons at Canberra Hospital. 'But in the lesser categories of disability, patients have admitted to having more difficulties than their doctors' reports indicate.'

Why might Australians with MS be reluctant to talk to their doctors, and presumably other health professionals? And, are doctors asking sufficiently probing questions of their MS patients? Dr Simmons asked over 2,700 AMSLS participants with MS for their suggestions, and collated these into broad categories.

First, according to people with MS it is important that doctors ask "How are you really?" within the obvious time-constraint of the medical consultation. 'But it is equally important that patients 'pipe up' about their hidden difficulties due to MS,' says Dr Simmons, 'even though you may not wish to be seen as a whinger, or go over old problems. The knowledge and skills of health professionals does change and increase over time, so don't short-change yourself out of getting the best possible assistance: Speak up!'



I am only likely to make a fuss if a totally new symptom was to emerge rather than an existing one that went up a notch in its severity.

My neurologist is pleased with my health. When I visit I don't talk about my feelings, frustrations or the little things that I grapple with such as fatigue, trying to keep my life together, etc. It would not occur to me to talk with him about these things, even though he is a very nice, kind man. I would feel like a hypochondriac or a whinger. He would consider my MS to be mild and show his pleasure that I am OK and life is going well for me. I quite like that he is happy with my progress, it's like being a "good girl". (Quote from survey)



▶ DR REX SIMMONS

As well as tracking information on the use and perceived benefits of conventional medications, the AMSLS also collects the first comprehensive, nationwide data on the use of complementary and alternative medicines (CAMs) by people with MS. It has discovered that the use of these can vary depending on age, sex and degree of disability of the person with MS. This will eventually allow health professionals to recommend particular CAMs that have been beneficial to certain groups at certain stages, for example, 'Here's a lady, in her 30s, she's likely to find benefit in meditation and yoga.'

'We know that women are twice as likely as men to seek philosophical and spiritual help with their MS,' says Dr Simmons. And there appear to be some cultural differences in the use of CAMs between Australia and the USA. Americans are more likely to use chiropractic and acupuncture therapies, and around 27% of Americans use prayer compared with ten percent of Australians. 'Americans tend to pray more' added Dr Simmons.

The AMSLS has also undertaken nationwide research into the economic impact of MS. The results were launched last year and showed that the total financial cost of MS in Australia was over \$660 million per year. When monetary estimates are added for loss of quality of life, the total comes to \$2 billion annually, a cost borne by those with MS, the government and the community.

The AMSLS has two major collaborative projects in the pipeline on quality of life in people with MS (in collaboration with staff at Griffith University in Queensland and MS Australia) and sexuality and incontinence problems in MS (Deakin University, Royal Melbourne Hospital, and MS Australia.)

The *Australian MS Longitudinal Study* is a project fully supported by MS Research Australia. It is currently funded by donations from Biogen-Idec, Sanofi Aventis, Schering and Serono, by a grant from the Alma Hazel Eddy Trust and by a donation from the Leongatha Auxiliary of the MS Society of Victoria.

Lions Club recognises group effort... and its leader

An item in the newspaper last year attracted the attention of a member of the Ku-ring-gai Lions Club.

Straight away he recognised there was something positive and powerful in what he read. The article was about the F5m launch (Foundation 5 Million).

Contact was made with Ian Ballard – NSW F5m Team Leader – suggesting that he would be an ideal recipient of the Club's 'Service to the Disabled' award. So after less than 12 months of F5m's existence Ian Ballard accepted one of eight annual awards given to different categories of service.

The Hon Dr Brendan Nelson is the Patron of Ku-ring-gai Lions Club and was there to make the announcement and present the award.

'I think the main thing that attracted the Lions Club to F5m is that it is based on involving people with MS doing something by themselves for themselves,' Ian said.

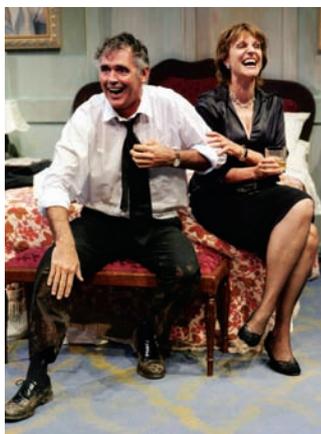
'Besides organising fundraisers, the intention is to provide a service to the community as MS sadly is on the increase. The actual idea – that 2,000 people with MS could raise \$2,500 each to get to \$5m – interested them as a novel, inclusive approach to fundraising,' he said.

F5m is a fantastic bunch of motivated people who want to do what they can to support research for a cure. It's a positive way to get things done and have a heap of fun while doing so.



▶ F5M'S IAN BALLARD WITH THE HON DR BRENDAN NELSON AT THE LIONS CLUB AWARD.

LOSING LOUIS - FEATURING ANDREW MCFARLANE AND LINDEN WILKINSON.



▲ You *have* to laugh

Raising funds... or a laugh? Either is good. One benefactor is doing both by purchasing an entire performance of 'Losing Louis' at Sydney's Ensemble Theatre in Kirribilli and donating it to us to sell – ALL 216 seats for the audience on Tuesday June 27.

What did six-year-old Tony see when he hid under his parents' bed 50 years ago? The secret is finally out in this darkly humorous farce about a not-so-happy family.

Simon Mendes de Costa's play has been described by the English press as 'tasty theatrical comedy', a 'big popular hit' and 'hilariously funny'.

Amanda Muggleton, George Spartels, Amanda Bishop and Andrew McFarlane star in this Australian premiere of 'Losing Louis', directed by Andrew Doyle.

For tickets for you and your friends, contact Susie Hope on 02 9555 4650 or email louisard@bigpond.net.au

MS research considers a new road – into Proteomics

In a new phase of proposed research and development, medical researchers working with MS Research Australia's (virtual) Neurobiology Research Centre are considering an alternative field of study in an effort to widen the possible paths toward a cure.

At an MSRA Research Roundtable conference in March, Professor Claude Bernard from Monash University indicated Australia's MS researchers are looking at proteomics. This innovative approach would involve a number of research centres around the country, in particular Professor Shaun McColl's facility at the University of Adelaide.

The proposal involves the study of proteins, particularly their structures and functions, and protein modifications associated with MS. This represents a move away from the more traditional examination through genomics. Genomics is the study of an organism's genome and the use of the genes. This genome structure does not change as the body is affected by nature, medication or disease.

In contrast, the proteome (the organism's protein make-up) is constantly changing and differs from cell to cell. This can make the study of proteomics a difficult process to track. However, MSRA is looking forward to taking on this new phase of research as a major new discovery platform that will enable direct observation of cellular molecules and their behaviour in processes related to MS.

Professor Graeme Stewart from the University of Sydney (Westmead Campus) feels this diverse and fresh research may create a new sense of urgency among the MS community and help raise funds through MSRA. 'We do all of this for one reason only – to improve the life of those people with Multiple Sclerosis and to prevent future generations from having it,' Professor Stewart said.

If this new research proceeds, the University of Adelaide would have an increased focus as a major centre for MS research in Australia. MSRA also hopes this development will attract more scientists into the study and at the same time allow them to collaborate their findings.

Hold a Garage Sale, and they will come!

It started out as a house clearance, with the contents of one home being up for sale. And it was going to take place in a suburban garage, until others got wind of the exercise and wanted to join in.

'I've had a garage that I've been wanting to get into for years,' said one MS supporter, so she added her clutter to the booty.

'Everyone saw it as a chance to clear out their cupboards,' said Yvonne McKeown garage sale organiser. Before long, a new venue was required for the mammoth garage sale to end all garage sales: The whole carpark of MS Research Australia in Chatswood. And it all happened on Saturday 1 April.

Signs up in local shopping centres to attract bargain hunters also managed to draw out more contributions. 'By the Friday before the big day, our offices were full of stuff,' said Yvonne, looking around the huge meeting room which has now, mercifully, been cleared of 'stock'.

'We had everything – clothes, toys and electrical goods including four brand new heaters from the original house which had been owned by an eccentric millionaire. Another woman was moving and wanted to achieve a minimalist look so everything had to go.' A case of un-decorating. The Northside Baptist Ladies joined the fray, setting up a cake stall. 'There was a true community spirit,' said Yvonne.

'Friends and family were recruited to run the sale. We even had my cousin fly up from Victoria to help out on the day.'

To date \$4,500 has been raised, with a smaller 'son-of-garage-sale' planned to clear the leftovers.



▶ GRAHAM BRYCE AND TRAVIS SIMON - SUPER SALESMEN.



▶ LIZ HAGGETT AT THE CAKE STALL

MSRA Partners



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Department of Health and Ageing

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The Campaign Coordinator
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