

MSRA Next



ABN 34 008 581 431

THE OFFICIAL NEWSLETTER OF MULTIPLE SCLEROSIS RESEARCH AUSTRALIA

MS research accelerates on many fronts – the National Programs:

As MS Research Australia closes in on its fourth birthday, we are excited about the increasing pace of MS research. Our collaborative networks and directed investment are culminating in a series of significant results that are attracting worldwide attention.

This has only been possible with the wonderful support from the MS community which has encouraged a range of individual projects (to be reported on in the next issue) and directly supports six major national MSRA research programs, featured here.

1. The Ausimmune Study – identifying the link between vitamin D and MS

This is one of the world's leading studies into the environmental exposures that influence the onset and progression of MS. With study sites in Brisbane, Newcastle, Geelong and

Hobart, the Ausimmune has been a successful collaboration between nine different universities and research institutions.

The team, managed by Prof Anne-Louise Ponsonby and Dr Robyn Lucas, from the ANU, is now analysing the data. Early indications show a significant correlation between MS, Vitamin D and glandular fever. The data requires further analysis, however we expect the results to generate several influential papers. The results will also inform decisions regarding a potential MS prevention trial.

The Ausimmune study was funded initially from the National MS Society (USA), with subsequent contributions from the National Health & Medical Research Council (NHMRC, a Commonwealth Government agency) and MSRA. This study has been able to achieve its objectives at a statistically relevant level that will make the results very important.

THE SYDNEY MORNING HERALD – 24 APRIL 2008

Telling the world how it feels

Johnny Hickleton's experience when he was diagnosed with multiple sclerosis inspired...

When the graphic artist Hickleton learnt that he had multiple sclerosis, the news was delivered with a brutality that stuns him still – almost seven years later.



Overseas travel a bitter pill for sick

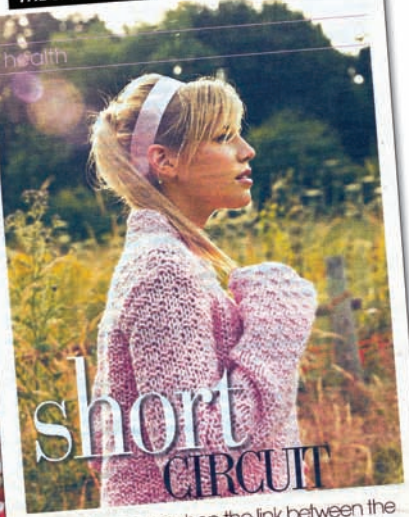
From Page 1... relapse leaves you with more signs of disability," she said.

THE DAILY TELEGRAPH – 27 MARCH 2008



Toni Powell, who has been battling multiple sclerosis for 25 years.

THE SUNDAY TELEGRAPH – 3 JUNE 2007



short circuit

What happens when the link between the body and the brain gets mixed up? Ask someone living with MS. By Linda Drummond

Imagine living with a condition where your brain tries to tell your body to move, but the message just doesn't get through. You might want to walk across the room. You know that you have to lift yourself up out of your chair and put one foot in front of the other, your feet are only bearing a muted, garbled demand – or nothing at all.

Banking on a new brain cure

Stuart Hickson is offering the world a cure for MS. He has a simple idea: to create a cell that would change the way the brain works.



David versus dread... artist Johnny Hickleton shares his...

although it can be confirmed in more than 90 per cent of cases by an MRI scan, which will reveal areas of damage, called lesions, on the spinal cord.

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Now Hickleton relies on a combination of the redative diagram and the anti-depression anti-inflammatory. It is not only a cure for MS, it is a cure for depression.

MS Brain Bank Progress

In response to our call for brain donations, we now have over 200 pledges and already 2 donations. This provides huge encouragement to Australasian researchers and will help develop the world class neuropathology in MS research.

For information call 1300 672 265 or visit www.msbrainbank.org.au

CONTINUED ON PAGE 2

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## 2. The ANZgene project – thousands of DNA samples – leading to better treatments

The cause of MS is likely to be a complex interaction between genetic and environmental factors. We know for instance that if a family member has MS, there is a significant increase in an individual's risk of developing MS. Genetics research will isolate candidate genes that may lead to an understanding of MS susceptibility, and perhaps develop new treatments.

A critical mass of researchers led by Prof Trevor Kilpatrick from University of Melbourne and chaired by Prof Jim Wiley from University of Sydney are now mobilised to develop an Australasian MS Genetics Consortium (ANZgene).

ANZgene has now collected 2,800 DNA samples from People with MS (PwMS) from all around Australia and is now recruiting another 1,500 samples from New Zealand. This gives the study high statistical validity to identify the genes influencing MS progression.

Currently 2,000 of these DNA samples are being analysed in the Diamantina Institute in Queensland to differentiate the genes between primary-progressive and relapsing-remitting MS. Another 1,000 DNA samples will be sent to Cambridge (UK) for a 'whole-genome' study of 10,000 samples from Europe and Australia.

In parallel with this, a team of neuroscientists and geneticists are looking at how the genes influence the course of MS. The result will hopefully lead to diagnostics that are able to predict susceptibility to MS and treatments that are specific to the genetic make-up of each patient.

## 3. The MS Brain Bank – providing human MS tissue for vital MS research

As reported earlier in the year, the national MS Brain Bank, led by Prof Simon Hawke, was launched by MSRA as part of the Brain and Mind Institute at the University of Sydney. In just three months, more than 200 PwMS nationally have pledged their brains to MS research.

Brain tissue will soon be providing samples for vital research on the cause of MS and will help accelerate the world-class neuropathology research that is already proceeding at University of Sydney.

## 4. The MS Longitudinal Study – how does MS affect people's lives?

This study, involving nearly 3,000 PwMS, has been tracking changes in the elements that contribute to an individual's quality of life, their financial position and adherence to appropriate therapies. Based at Canberra Hospital, Dr Rex Simmons coordinates this study with regular questionnaires distributed nationally.

Dr Simmons' findings are regularly communicated to MS Societies and neurologists, to feed statistically significant results to inform and improve current clinical practice. He has also provided data for a major Economic Impact Report that has helped influence government policy. Upcoming results will generate a re-evaluation of this Report, and several publications

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involving usage of the Pharmaceutical Benefits Scheme by neurologists, and complementary medicines by PwMS.

## 5. The MS Clinical Trial Network – let's keep in touch with new treatments

Clinical trials are important studies that test new and better ways to prevent, diagnose and treat MS. The Australian MS Clinical Trials Network is currently being coordinated by MSRA to link biotechnology and pharmaceutical companies with neurologists and PwMS. It aims to coordinate the current ad-hoc procedures for MS clinical trials nationally and will encourage new trials to be undertaken in Australia. If the (many) new treatments for MS can be tested in Australia, it will provide PwMS with early access to better treatments.

## 6. New scholarships and fellowships – populating the MS laboratories

Young talented researchers are vital for laboratories undertaking critical MS research. MSRA keenly supports researchers at the early stages of their career to develop their interest in MS research with the hope that they continue to pursue it until a cure is found. MSRA offers several opportunities including the Betty Cuthbert Scholarships and Fellowships, in partnership with the NHMRC, and the new Macquarie Group Foundation, Australian-UK Research Fellowship.

The Betty Cuthbert Scholarships and Fellowships are for the top new Australian researchers in MS and MSRA funding is matched with funding from the NHMRC. So far we have initiated three Fellowships: For Dr Helmut Butzkeuven, Dr Junhua Xiao and Dr Tobias Merson, all at the University of Melbourne.

In our last newsletter, we announced that MSRA in collaboration with the UK MS Society, had initiated the world's first International Fellowship dedicated to MS research. This fellowship – supported by Macquarie Group Foundation – will allow an outstanding researcher to come to Australia or one of our best to travel to the UK, to work with one of the best MS research labs in the country. This will considerably strengthen our global research cooperation.

## Bringing together Australia's brightest researchers

Much of this new research has been generated by an ability to bring the relevant scientists together. Before MSRA was established in 2004 there was no national focal point for MS researchers in Australia. Since that time, we have helped mobilise the MS research community. MSRA is now a contact point for MS scientists working in over 20 medical research institutes around Australia.

According to Professor Trevor Kilpatrick, Head of Australia's largest MS research team, based at University of Melbourne, 'MSRA has changed the landscape of MS research in Australia.' This coordination has resulted in improved collaboration and cooperation between MS researchers around the country – and a doubling (at least) of the research activity involved.



## Big Bequest

**When Jule Rigby passed away in October 2007, she left a legacy aimed at changing people's lives.**

Ms Rigby, a former nurse who lived in the NSW Southern Highlands, was the aunt of F5m founder Ian Ballard and she bequeathed her entire estate to F5m. Ian was diagnosed with MS 14 years ago, and says that he was not aware before her passing that she would leave so much money to the foundation but that it was typical of her caring personality. The sale of Ms Rigby's house was finalised last month, boosting F5m's fundraising tally by more than \$200,000.

F5m and MS Research Australia naturally welcome further bequests to directly benefit the research effort.

▶ IAN BALLARD WITH JOAN JACOB, A FRIEND OF HIS LATE AUNT JULE RIGBY.

## Lina is honoured ... and gets a Neighbours spot!

**Supporter Lina Marrocco was honoured with an Order of Australia Medal at this year's Australia Day awards.**

Lina established a fundraising organisation called Charityworks which raised money for the Melbourne Children's Hospital many years before she was diagnosed with MS in 2000. After her diagnosis she kept the fundraising energy, switching the cause to finding a cure for MS. To date Charityworks for MS has raised more than \$270,000, with the last ball in 2006 raising \$147,000. Her next Charityworks Ball for MS will take place on 22 November, 2008 at the Grand Hyatt Melbourne.

Lina has been involved in many activities besides the ball – she most recently spent a day on the set of *Neighbours* playing herself as the prolific fundraiser she is, opposite actor Jackie Woodburne whose character Susan has MS on the show. The show will go to air on 17 June.

## Becoming a fundraising hero just a click away

**Some F5m champions have been able to raise awareness and funds through the Internet.**

'Everyday Hero' allows individuals to register their own efforts online, giving friends and strangers alike an easy way to support them. Katrina Hemingway, whose husband Mike has MS, is using the site to raise money for her trek along the Kokoda Trail. Also, F5m Campaign Administrator Neil Robertson is using the site for his trip around Australia. Called 'Are we there yet?' Neil will be travelling in a caravan around Australia for three months starting July. He is taking his wife Belinda and two young sons for support! They will be dropping by F5m supporters around the country, so watch out!

See Katrina and Neil's page through the site – [www.everydayhero.com.au](http://www.everydayhero.com.au). You too can set up your own page easily. If you have a challenging event you think people might like to sponsor, you can set up the page so anyone who wants to support MS research can do so.

## Bountiful birthdays



▶ TINA POLIOS (FOREGROUND, AT RIGHT) AND FRIENDS MASQUERADE FOR HER BIRTHDAY AND FOR MS.

**Congratulations to two birthday girls who turned their parties into major fundraising events.**

Both Ainsley Forrest from Adelaide and Tina Polios from Sydney asked that in lieu of presents, their guests make a donation to F5m. Ainsley's 30th party brought in nearly \$4,000, while Tina's Masquerade Party raised \$3,175. Our thanks to everyone who attended and gave generously.

## Coming up

**The MyStery Ball** is looking to be one of the most glamorous nights of the year, with a cocktail party at the Australian Museum. It will take place on 9 August, and there are just 400 tickets so book early! Interested? Then you should contact Rob Warren, one of the event's organisers, at [rwarren@colonialfirststate.com.au](mailto:rwarren@colonialfirststate.com.au). More information at [www.themystery.org.au](http://www.themystery.org.au)

**Throw the Book at MS** – this wildly successful book-inspired Trivia Night is on again. A live event will take place on 4 June at Paddington Town Hall in Sydney, but all book clubs are invited to make this into a national event by hosting their own trivia night. For tickets to the event or to receive the questions contact Johanna, (02) 9360 4128 or [johanna@dwyers.optusbiz.com](mailto:johanna@dwyers.optusbiz.com)

## Smooth sailing brings in \$20k

### An afternoon of sailing races on Pittwater in Sydney's north resulted in a big win for MSRA.

The Association of Financial Advisors (AFA) organised the April regatta, which raised nearly \$20,000. Three of its members, Brian Boggs, Charles Smith and Pat Chick donated their personal Beneteau yachts for the day.

The Pittwater event was hosted by John Strong of Strong Financials and Patrick Bourke of Ayers Management who purchased the regatta in an auction held during the AFA National Conference last year.

Before the guests climbed into the boats, senior genetics researcher Fiona McKay from Westmead informed the crews of the latest in MS research.

Although the breeze was not as strong as the competitors would have liked, there was healthy competition on the water. The ING team came out on top, triumphant in two of the three races.

Many thanks to corporate sponsor ING for their support and also to Vicsail which donated full catering.



► POLICE MINISTER INCOGNITO!

## Audi AFA MSquerade Ball

Queensland's most glamorous hid their faces on April 19 for a very special event. The MSquerade Ball at the City Hall drew 500 guests, including the Queensland Police Minister Judy Spence, all shrouded in spectacular masks.

On the night, the masked theme was brought to the stage, as opera performer and PwMS Toni Powell performed works from the masquerade segment from Phantom of the

Opera. Toni had previously acted the part of Carlotta in the stage musical which toured around the country, and her recital brought the crowd to their feet.

The total funds raised by the event was \$175,000, with \$50,000 taken on the night. This will be divided between MSRA and the MS Society of Queensland. The MS Society will direct the funds towards independent living apartments in Queensland for PwMS and to Queensland research projects.

This event was also the launch of the 'Thanks A Million' project which aims to raise \$1million for the cause in 2008.

MSRA extends special thanks to Mairead, Jacqui and the team at the MS Society of Queensland for organising such a fantastic inaugural event.

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