



MS at work

National MS Employment Survey starts July 2010

People with MS have more difficulty maintaining employment than people with other chronic diseases such as diabetes or heart conditions.

Data from the Australian MS Longitudinal Study (led by Dr Rex Simmons of Canberra Hospital, 2003-2007) shows Australians with MS have a high unemployment rate and primarily leave paid employment due to difficulties with MS symptoms.

The study suggests earlier planning for employees' various workplace arrangements is needed to cover possible future disability levels. Valid concerns cited in the study include anxiety about employer discrimination. However many companies have far-sighted employment policies.

Kim Schmidt, Woolworths Limited's Director of Human Resources has increased the number of Woolworths employees with a disability.

"We serve more than 14 million customers weekly. So it is essential our workforce reflects the community it serves," Ms Schmidt said.

Neil Cockroft, Head of Diversity and Inclusion at National Australia Bank (NAB), said the bank sees people with a disability as a source of potential talent.

"While situations differ for people with MS," Mr Cockroft said, "solutions can often allow individuals to continue making a valuable contribution to their organisation. This represents a 'win' for both parties".



In July 2010, the National MS Employment Survey will begin collecting annual statistics on employment hours, conditions and employment changes. It will also ask about disability and employment difficulties. People diagnosed with MS, aged 18-65 who are in current paid employment are invited to complete the survey.

Results from the National MS Employment Survey will significantly add to the ongoing knowledge base and fine-tuning of employment programs for People with MS by MS Societies and other agencies.

To join the study, call Dr Rex Simmons at Canberra Hospital on 02 6244 4228



New cyber-face of MSRA

Meet the new-look MSRA at our redesigned web site – www.msra.org.au

The design is easier to use so you can quickly find the information you want on MS research, fundraising and more. Anyone interested in the latest MS research news can also find MSRA on Facebook and Twitter.

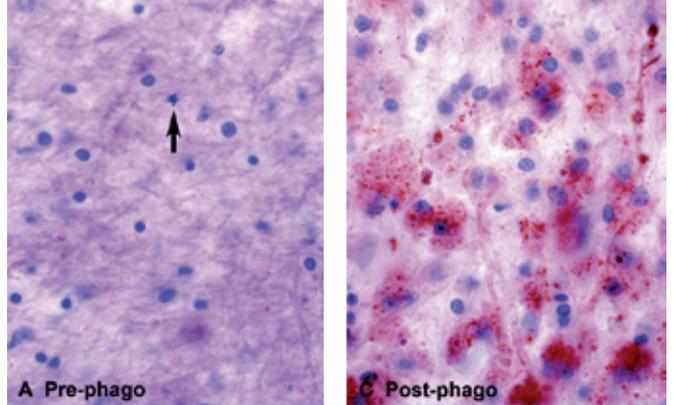
Making the most of your brain

The key to multiple sclerosis could lie within the brains of people with MS themselves and that's why researchers rely on the foresight of MS patients and their families to donate post-mortem tissue to the MSRA Brain Bank.

Examination of newly formed lesions of MS patients who died during or shortly after the onset of an acute relapse has provided crucial insights into the disease. It appears that oligodendrocytes – the cells forming the insulating myelin sheath around neurons – are dying before large numbers of inflammatory cells are present (1).

This suggests that macrophages, seen to be ingesting myelin in MS lesions, are actually removing the debris of already dead oligodendrocytes instead of destroying healthy myelin as was previously thought. Subsequent inflammation from the recruitment of additional immune cells to help in the clean-up then amplifies the demyelination process and causes further tissue damage.

This new finding challenges traditional MS autoimmune theory and could explain why current anti-inflammatory



STAGES OF MS LESION FORMATION: (A) ARROW POINTS TO A DYING OLIGODENDROCYTE, MYELIN STILL INTACT; (C) MYELIN INGESTED BY MACROPHAGES AND BROKEN DOWN INTO LIPIDS WHICH STAIN RED.

therapies only relieve symptoms early in the disease and don't protect against progress to later stages of MS (for which there is no known treatment).

There is, however, clear evidence of tissue repair and remyelination. Researchers are now investigating why some people's nerve tissues naturally heal better than others' – with hopes of discovering restorative treatments to promote cell regeneration and reverse tissue damage.

During the past two years, 18 brains have been donated and more than 400 people have signed as brain donors for MS research.

You can make the most of your brain by calling **1300 672 265** or submitting your details online at **www.msbrainbank.org.au** to request a brain donor information pack. Your contribution will be truly appreciated by all who seek a cure for MS. ■

(1) Andrew P. D. Henderson, Michael H. Barnett, John D. E. Parratt, and John W. Prineas. Multiple Sclerosis. Distribution of Inflammatory Cells in Newly Forming Lesions. *Ann Neurol* 2009; 66:739-753.

Walking and balance

Study looks at balance, mobility and falls risk in people with MS

MSRA is funding a new study on the effect of prolonged walking on balance, mobility and risk of falls in People with MS (PwMS).

"Currently, there is limited evidence as to the ideal way to help PwMS with mobility difficulties", said the study's principal investigator, James McLoughlin of Flinders University, South Australia.



■ JAMES MCLOUGHLIN IN ACTION.



Mobility issues are a major cause of disability for PwMS. Fatigue appears to be the greatest limitation for walking. However, the correct combination of exercises and/or simple orthotics could help reduce the effects of fatigue on mobility and reduce the risk of falls.

MSRA will fund the research for 18 months. It will investigate the changes to an individual's gait and standing balance after six minutes of walking in PwMS who have mild to moderate disability. A simple orthotic – around the ankle and underneath shoe laces – will be tested to see if it may limit the detrimental effects of fatigue and reduce the risk of falls.

James has over 10 years' clinical experience working closely with PwMS; as Senior Physiotherapist at the MS Society of SA and NT, St Georges Hospital, London and in private practice in Adelaide.

The study requires 40 participants living in the Adelaide area diagnosed with MS and living with mild-to-moderate mobility difficulties.

More information is available on the MSRA Clinical Trials Network website: **www.mstrials.org.au** ■

Much more than funding bodies

MSRA's community fundraising initiative, Foundation 5 Million (F5m) has many devoted and committed supporters and affiliated groups who work tirelessly raising funds for research into MS.

Two of these affiliated groups, The Trish MS Research Foundation and CharityWorks for MS have been extremely active in the development of MS research, from before MSRA was established. They have since joined the F5m team and together we are able to fund many more promising projects.

CharityWorks for MS was established in 2006 by Lina Marrocco and a team of dedicated volunteers who have a personal connection with the disease. Based in Melbourne, CharityWorks for MS has focused on funding and assisting the development of Melbourne MS research at the Florey Neuroscience Institutes. Examples of some of these projects are detailed below:

In 2009 CharityWorks for MS funded **Dr Judith Field** in her investigation of how genetic changes in People with MS (PwMS) affect the disease development. Dr Field has already seen indications that small genetic changes play a role in immune regulation and can dramatically affect gene expression. This work could shed light on both the mechanisms involved in the disease pathogenesis and lead to more targeted treatments.



Dr Melissa Gresle was funded to develop a new blood test for brain injury in people with MS. This project will enable Dr Gresle to determine if it is possible to measure neurodegeneration from blood. If so, this could lead to clinical trials of neuroprotective therapies and hopefully new drugs to prevent neuron damage.



Please show your support for the bi-annual CharityWorks for MS fundraising gala – Diamonds, diamonds, diamonds, the Jewel in the Crown, being held this year on August 21 at the Palladium at Crown. ■

The Trish MS Research Foundation, established in 2000 by Roy and Carol Langsford in honour of their daughter, have funded many MS research projects. Examples of some of these are:

Dr Ben Emery, at The University of Melbourne, recently identified a “master gene” that turns other genes on and off. His work aims to characterise how this gene promotes myelination and also to assess the role of the gene in myelin repair. Dr Emery hopes this study will generate strategies to promote myelin repair.



A/Prof Helmut Butzkueven at the Florey Neuroscience Institutes is investigating the role of a molecule called Dab2 in response to autoimmune axonal injury in the central nervous system. A/Prof Butzkueven has already discovered that immune cells make up this molecule and the cause of nerve cell damage. The resulting axonal injury is currently irreversible and the likely cause of progressive disability in MS.



Dr Fabienne Brilot-Turville at The Children's Hospital, Westmead will study the role of humoral immunity (B cells and antibodies) during a first episode of demyelination. The protein MOG is thought to be one of the main targets of the autoimmune attack. Dr Brilot-Turville is studying the early signs of an autoimmune response to MOG.



You can support the Trish MS Research Foundation by attending the Sporting a Dream for MS Ball on September 18. ■

A FUNDRAISING GALA BROUGHT TO YOU BY CHARITYWORKS FOR MS
PROUDLY SPONSORED BY MACQUARIE GROUP LIMITED

Diamonds, diamonds, diamonds
The Jewel in the Crown

Date: Saturday 21 August 2010
Time: 7:00 pm - 1:00 am
Venue: Palladium at Crown
Whiteman Street, Southbank, Melbourne
MC: Sam Kekovich
Dress: Black Tie
Cost: \$175 per person
(includes 3 course meal and drinks)

FOR TICKET BOOKINGS
Contact Jessica Lightfoot
tickets@charityworks4ms.net.au

FOR FURTHER INFORMATION
Please visit
www.charityworks4ms.net.au



THE TRISH MULTIPLE SCLEROSIS RESEARCH FOUNDATION'S

SPORTING A DREAM FOR MS BALL

IF WE DARE TO DREAM LIKE SPORTING LEGENDS DO,
WE CAN FIND A CURE FOR MS

Date: Saturday 18 September 2010
Time: 6.30pm to 12.30am
Venue: Hilton Sydney, 488 George Street, Sydney
Tickets: \$160 each
Includes: Pre-dinner drinks, 3 course meal, beer, wine and soft drinks
Dress: Lounge Suit
MC: Mark Beretta – Channel 7's Sunrise
Guest of Honour: Ken Rosewall AM MBE – Australian Tennis legend

For ticket bookings contact Roy or Carol Langsford on 0410 410 491

OFFICIAL INVITATIONS AND BOOKING FORMS
WILL BE AVAILABLE 24 JUNE.

FOR FURTHER INFORMATION PLEASE VISIT
www.trishmsresearch.org.au





MS1000



MLC Risk Riders



The Great North Walk

Walking across Spain for love

Josephine Grieve and her two daughters, Luna & Rosa, are walking the Camino de Santiago, the well-worn path in northern Spain. Their husband and father, Felipe Rodriguez,

who has MS, comes from an area near their destination. Felipe and Josephine always dreamed of doing the Camino when the children were old enough. Although Felipe wasn't able to do the walk himself he was the inspiration for the dream being turned into a reality. The girls are not only walking across Spain for love, they are walking to help



find a cure for MS. To support this fantastic effort please visit <http://felipewithlove.blogspot.com> ■

Marathon fundraising month

The March marathon month raised over \$110k with a tremendous effort from four fantastic events. Congratulations and special thanks go to all of the inspiring participants and dedicated support crews;

- The MLC Risk Specialist Network team who cycled 400km in the Risk Ride for MS research.
- Cory Pearce, Andrew and Scot Edwards, Simon Hughes and Nick Hodder who organised and participated in the MS1000 which involved paddling, cycling and hiking.
- Tim Charleson and 15 colleagues from John Holland Constructions, who rode in the Three Peaks Challenge.
- Phil Salter, Michael Coates and Jon Mckenzie, from the NAB, walked 250km on the Great North Walk.

Raise dollars not stress levels

Want to raise money for F5m ... but don't want to organise the entire event? Join an event in your state, such as the City2Surf, Run Melbourne or Run Gold Coast. Both Everyday Hero and GoFundraise websites make it easy to create your individual or group fundraising page. So why wait? With an F5m singlet to support your campaign, set up your fundraising page and drop us an email at: info@F5m.org.au with your details and fundraising goal, or call 1300 356 467. ■



ROB HEARD (LEFT) WITH ANNE KIRKPATRICK AND HER BAND.

Our rocking researcher

Talented musician and a respected MS researcher A/Prof Rob Heard, welcomed family and friends to his property at Ourimbah Creek Valley for a commemorative Ourimbah Music Festival. Close to 40 years earlier the same valley hosted a similar festival called 'Pilgrimage for Pop'. The 2010 anniversary event raised valuable support and awareness for MS to a very responsive audience.

Rob is an accomplished keyboard player for Sydney band, *Faux Pas*, and attracted several Australian music legends including Anne Kirkpatrick, Jim Conway and Mike McClellan. ■

Ready for a challenge? Walk Mudgee2Sydney

Katrina Hemingway and Elizabeth Melchior conquered Kokoda in 2008, raising \$33,000 for F5m. This year the goal is to raise \$100,000 on the 'Mudgee2Sydney Walk for MS research' – starting on September 12 covering 270km in 11 days. There are various walk and ride options and you are invited to take part in any of the legs. Alternatively,

volunteers are needed to join Katrina's husband Mike, on the support team. Volunteers already include Fiona Hall, Susie Hope and Wendy Stevens. Help us walk towards a world free of MS. Contact us on 1300 356 467 or www.m2s.org.au ■



Sporting partners



MSRA is delighted to announce two new sporting partnerships for 2010. This year MSRA is a charity match partner for both the NSW Swifts netballers and the Manly Sea Eagles rugby league team.

MSRA's partnership with the NSW Swifts is especially fitting because MS affects three times as many women as men. The Swifts are NSW's state netball team and are climbing the top rungs of the national ANZ Championship ladder. They recently supported MSRA in their match against the Queensland Firebirds on 17 May. An MS Awareness

Week advertisement was screened, volunteers handed out MS information and donations were collected post-match.

One of Australia's top NRL teams, the Sea Eagles will also support MSRA at their match against the Bulldogs on the weekend of 3-5 September (exact date to be confirmed) via promotional activities and donation collection. If you would like to attend this special match to support MSRA and the Sea Eagles please visit www.mwse.com.au

Both teams recently participated in the new 'Kiss Goodbye to MS' campaign launched on World MS Day, 26 May 2010.



ABOVE – NSW SWIFTS PLAYERS REBECCA BULLEY AND VANESSA WARE WITH RED LIPSTICK FOR MS AWARENESS WEEK.

LEFT – THE MANLY SEA EAGLES IN ACTION.

The campaign on everyone's lips!

This year's MS Awareness Week will be on everyone's lips ... truly!

'Kiss Goodbye to MS' embraces the idea that we all aim to say goodbye to the impact of MS on lives, the uncertainty it brings and farewell to the disease itself.

With a theme this year of employment, there was a chance to open a discussion about the impact of the disease on PwMS and their families, carers, and employers. An international survey was released, to which Australia's Dr Rex Simmons was an important contributor (see page 1). Among its findings is a message: talk to your employer about your MS. At least it can alleviate some of the anxiety and at best it leads to discussion of flexibility to better manage symptoms, medication and work.



Hence the need to put it on everyone's lips! So on World MS Day, May 26, maybe you noticed everyone wearing red lipstick to support the cause. Events were held in Martin Place Sydney and at venues around the country. Men got involved too by purchasing a 'kiss' tattoo for their cheek (or a real one!). Visit www.kissgoodbyetoms.org and join the Facebook group. ■

Australia in top gear with international partners



MS Research Australia works in partnership with researchers and funding organisations around the world.

One of these is the Accelerated Cure Project. This US-based not-for-profit started when technology entrepreneur, Art Mellor, diagnosed with MS in 2000, began investigating the disease and potential cures. He found little was known about root causes and he felt much greater organisation and collaboration was needed. He formed the Accelerated Cure Project to provide information, leadership and resources to accelerate world knowledge on the causes and disease mechanisms of MS.

Its first project was a 'cure map', which analysed what was and was not known of causes of MS – to determine what needed to be done. Findings on different types of factors that could cause or trigger MS – genetics, nutrition, infectious agents, trauma, and toxic agents – were analysed. To make those studies possible, the Accelerated

Cure Project launched its chief scientific resource: a biobank or repository for MS research. The MS Repository is a large-scale multidisciplinary bank of matched controls, blood and data samples collected from people with MS and other demyelinating diseases.

MSRA is exchanging information and working with some of the same researchers who use this MS Repository. Prof Philip DeJager at the Harvard School of Medicine, for instance, is working closely with MSRA's ANZgene researchers and is part of the international genetics consortium.

More than 2,000 people have donated blood and data, in samples collected at 10 MS clinics across the United States. More than 30 research studies are currently using Accelerated Cure Project's repository samples. These studies' goals range from creating diagnostic tools to identifying genetic factors affecting MS risk and progress. For a list of active studies on samples from the repository, visit www.acceleratedcure.org/repository/research.php



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.
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Card No: _____
Exp: ____/____ Signature: _____
 - OR I have enclosed my: Cheque/Money Order payable to MS Research Australia.
- Title: _____ First Name: _____ Surname: _____
Address: _____
Suburb: _____ Postcode: _____
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.