



## Lessening lesions

**Despite the potential for MS lesions to occur anywhere in the brain or spinal cord, many people develop lesions in specific areas of the brain.**

MS lesions form when the immune system attacks the brain or spinal cord, stripping myelin off the nerves, sometimes damaging them in the process.

Lesions disrupt signalling from the brain to the rest of the body. However, soon after they develop the body has a natural capacity to repair these sites of damage.

Over time this process fails and lesions persist in causing debilitating and progressive disability.

Dr Judith Greer at the University of Queensland is in the early stages of testing a drug that could stop these lesions from occurring in certain parts of the brain.

Myelin proteolipid protein (PLP) is the most abundant protein in myelin and immune attacks directed against this protein seems to influence the locations in which the lesions develop. Dr Greer's research has identified this and generated a targeted new therapy. This could potentially stop MS lesions from developing in certain areas.

Dr Greer's work focuses on lesions that develop in the cerebellum and brainstem. The former is important for coordination and balance, while the latter is responsible for controlling breathing, swallowing, body temperature and sleep. Disruption to one or more of these important physiological functions is dangerous.

Dr Greer was one of the first researchers in the 1990s to identify that myelin PLP can induce different patterns of MS-like disease in animal models. Her research went on to



DR JUDITH GREER (FRONT CENTRE), WITH RESEARCHERS AT THE UNIVERSITY OF QUEENSLAND.

show that individuals with certain genes were more likely to have an immune attack against PLP and develop lesions in the cerebellum and brainstem.

Jeremy Wright, Executive Director of MS Research Australia (MSRA), said 'Dr Greer is acknowledged by her peers as an authority on PLP and we are encouraged that her knowledge is now focused on generating discoveries and treatments to help People with MS.'

Dr Greer believes that 'this drug has the potential to very specifically switch off the cells that are causing lesions in these areas and dampen down the immune attack in the brain'.

She has received a MSRA research grant in 2010 to extend her work. This would not have been possible without the generous support of the Sydney MS Angels and the Bizzell Foundation in QLD. ■



*Dr Greer is also participating in another major project – the MS Proteomics Collaboration including the University of Adelaide, University of Western Australia and Monash University. This project is looking at cells in the very early stages of MS and is supported by a new fundraising initiative 'Queenslanders for the Cause' to be launched shortly in Brisbane. See the MSRA website for more details [www.msra.org.au](http://www.msra.org.au)*

# CCSVI and MS

**MSRA is funding a new study to test for 'chronic cerebrospinal venous insufficiency' (CCSVI) in patients with MS. Recent studies have suggested a role in the narrowing or obstruction of veins in MS.**



A/PROF BRIAN CHAMBERS, AUSTIN HOSPITAL IN MELBOURNE.

A/Prof Brian Chambers from the Austin Hospital (Melbourne) is the Principal Investigator in this study. It will add to an increasing pool of knowledge; independently assessing whether there is significantly higher prevalence of CCSVI in MS patients compared to people who do not have the disease.

The study involves 100 patients with MS (cases) and 100 People without MS (controls). Study participants will be selected from the local neurological database of Austin Hospital patients. The study will involve testing for venous obstruction using ultrasound, with results available early next year. The same protocols used by Doctors Zamboni and Zivadinov, who recently described CCSVI, will be used in this study.

Meanwhile other studies published in the Annals of Neurology are challenging the role of CCSVI in MS. One of these studies was undertaken with 56 MS patients and 20 people with no neurological condition. Researchers were unable to detect a significant difference in venous drainage between those with MS and those without.

To resolve the conflicts surrounding CCSVI and its role in MS, MS Societies around the world have expedited funding for high quality research. The US National MS Society and MS Society of Canada announced a commitment of over \$2.4 million to support seven new grants to determine the role of CCSVI in the MS disease process.

In the meantime, People with MS who have questions regarding CCSVI and associated treatments are encouraged to seek the advice of their neurologist. MSRA's position on CCSVI is summarised at [www.msra.org.au/ccsvi](http://www.msra.org.au/ccsvi)

## Clinical Trials – Phase I



**Your participation in clinical trials can help find a cure for MS.**

A clinical trial (also called clinical research or a clinical study) aims to ensure treatments that are administered are safe and effective. Trials can also be used to learn how the body and disease responds to a treatment. This may open a window into the disease and how it works with the aim to develop better treatments.

Clinical trials are undertaken in carefully monitored and regulated phases:



Phase I trials are the first of several hurdles a new treatment must jump before it can reach patients, making it a critical step in the life of promising new treatments. The intention of Phase I is to find out the safe dosage, side effects, how the body copes with the treatment and if the treatment affects MS.

Currently there is a Phase I trial underway at the Austin Hospital Neurology Department and the Centre for Clinical Studies to investigate the use of an experimental drug in

MS. The study is suitable for people with relapsing MS, aged between 18 and 55 years and who are not currently on treatment. For more information contact the Centre for Clinical Studies on 1800 243 733 or email [contactus@centreforclinicalstudies.com](mailto:contactus@centreforclinicalstudies.com)

To review a list of all current clinical trials including opportunities to participate, please visit the MSRA Clinical Trials Network website: [www.mstrials.org.au](http://www.mstrials.org.au)



FIONA HALL VOLUNTEERING AT AN F5M EVENT.



CAROL COOKE IN TRAINING FOR THE 2012 PARALYMPICS.

## Hidden costs of MS

### **A vibrant young woman in the prime of her life, Fiona was diagnosed with MS in 1981, aged 27, whilst living in Bermuda.**

She had health insurance but no form of life cover or trauma insurance as it did not exist at this time. Still vibrant, Fiona now lives in public housing in Sydney and survives on a disability pension supplemented by income received from various contract jobs.

With almost 20,000 Australians currently living with multiple sclerosis (MS), awareness is increasing. However, many people are not aware of the potentially devastating financial impact on those involved and indeed on the whole community.

To promote the need for insurance, MSRA recently collaborated with the Investment and Financial Services Association (IFSA) on their Lifewise initiative. Lifewise aims to open discussion about underinsurance and encourage Australians to protect themselves from the financial hardship that can result from accident, sickness or unexpected death.

MSRA is also working with Government and the financial services sector to increase awareness of the need for insurance and insurance options for people already diagnosed with a chronic illness. We have provided data on the economic impacts of MS, including the high loss of employment by Australians with the disease. This data is gathered from the Australian MS Life Study (AMSLS), an ongoing national tracking study, based at Canberra Hospital.

MS costs the Australian economy over \$2 billion each year, with an estimated \$150 million due to lost productivity. Also, People with MS pay \$160 million per year out of their own pockets in health costs, yet 80% of People with MS are no longer in full time employment within ten years of diagnosis.

Fiona survives on \$235 a week for her food, electricity, gas and telephone bills. Her financial uncertainty has had a significant impact on her health and her personal relationships.

*'Life can throw some surprises and when you are young you tend to think you can roll with them. Income protection and life insurance were just not on my radar,'* she said.

In recent weeks, MSRA has attended the annual roadshows of both the Association of Financial Advisors (AFA) and insurance company AXA. Fiona was one of two keynote speakers for AXA, educating financial planners on the impact of chronic illnesses such as MS and the need to advise their clients on appropriate insurance.

Carol Cooke was the other speaker – a talented athlete, Carol was diagnosed with MS in 1998. Carol was lucky enough to have taken out insurance before diagnosis, which means she has relative financial security to adapt her lifestyle and focus her energy on her passions without MS holding her back. One of these passions is rowing – a sport Carol discovered after diagnosis – and Carol now has her sights set on representing Australia in the 2012 London Paralympics.

Carol's motto is 'Nothing is impossible if we dare to face our fears and believe in ourselves' and she says 'the greatest pleasure in life is doing what people say you cannot do.' Without insurance Carol would have had to spend more time managing her day to day life and less on following her dreams.

In order to find out more about insurance options visit [www.lifewise.org.au](http://www.lifewise.org.au)

To find out more about the AMSLS visit [www.msra.org.au/amsls](http://www.msra.org.au/amsls) ■

# The 'Black Hole' of MS



**Magnetic resonance imaging (MRI) is an important tool for confirming a clinical diagnosis of MS. It is commonly used today by neurologists to monitor the disease progression too.**

New areas of active inflammation and demyelination show up as bright spots on scans of the brain and/or spinal cord (Figure 1). These may disappear after a month or so, when the lesion has healed and symptoms improved. Some plaques, however turn into 'black holes' where myelin has been completely lost and nerve cells have been damaged beyond repair (Figure 2). Why some plaques heal and some do not is still a mystery, but it is clear that the number of MS lesions often correlate with a patient's disabilities.

To date, most research has focused on analysing MS plaques in the white matter of the brain. They are visible on MRI scans and can be identified with the naked eye on postmortem brain tissue (Figure 3). There is now however, increasing evidence that there is a more general problem in the MS brain that may not be related to plaques of demyelination. For example, studies of the normal looking white matter in MS patients indicate that it is not 'normal' at all, compared to the white matter of people without MS. This may in part be attributed to disease in the grey matter of MS patients, in particular those with progressive MS, where there is significant tissue damage and general loss in brain volume.

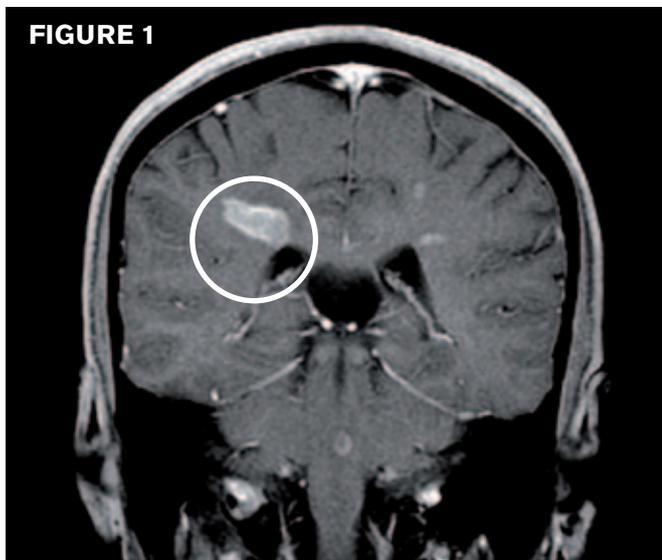
Changes in grey matter and normal appearing white matter caused by MS are undetectable using MRI technology. They can only be studied from postmortem tissue donated to brain banks by patients who had MS. These brain donations are extremely valuable to research.

If you would like to register to help MS research, and join 470 others who have already pledged, please call **1300 672 265** or visit **[www.msbrainbank.org.au](http://www.msbrainbank.org.au)** to request a brain donor information and consent pack.

Note: Being an organ donor does not automatically include brain and spinal tissue donation. Separate consent is needed for medical research.

Remember, **we have the brains to cure MS!** ■

**FIGURE 1**



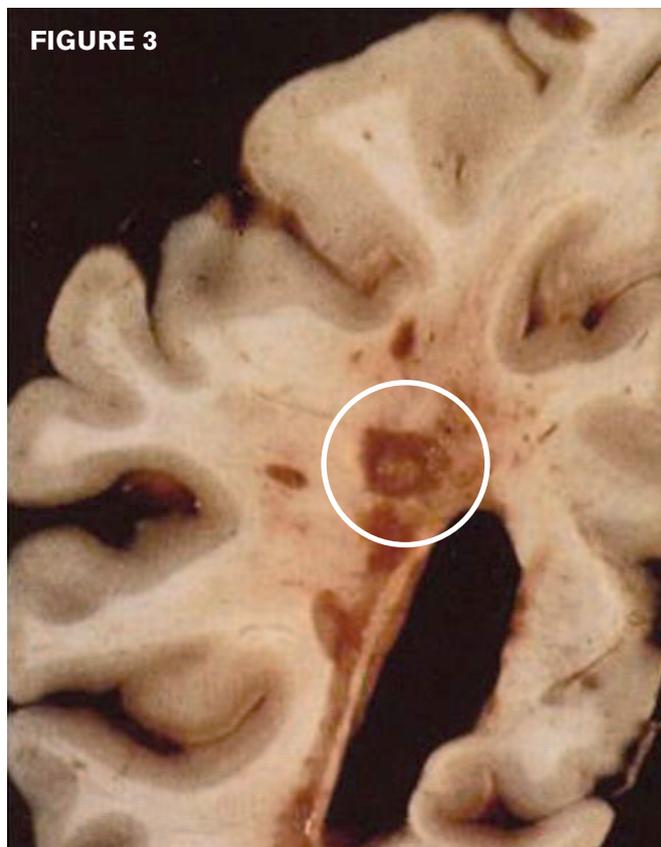
GADOLINIUM-ENHANCED MRI BRAIN SCAN SHOWING BREAKDOWN OF THE BLOOD-BRAIN BARRIER IN A NEW MS LESION.

**FIGURE 2**

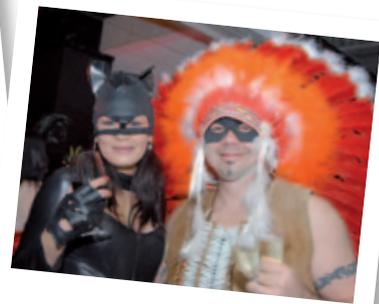


T1-WEIGHTED MRI BRAIN SCAN SHOWING A "BLACK HOLE" WHERE BRAIN TISSUE HAS BEEN LOST AS A RESULT OF INFLAMMATION IN AN MS PLAQUE.

**FIGURE 3**



MS LESIONS (BROWN AREAS) IN A SLICE OF HUMAN POST-MORTEM BRAIN.



## Doing it for theMSelves across Australia.

F5m is and always will be about People with MS, their family and friends, who are all driven to fundraise for a cure for MS.



**PETER ABOUD.**

Peter Aboud, a person with MS for over 30 years, is the 'driving' inspiration behind the annual **Blue Mountains Golf Day** at Leura Golf Club. This event is in its 4th year and has previously raised over \$26,000 towards research. This year's event is set

to be an outstanding day of golf in the mountains on Friday 1st October, non golfers are also welcome. To book please call Leura Golf Club on 02 4784 1503. Entry fee is \$30 which includes BBQ.

Fiona DuRieu is another incredible person with MS who has amazing passion for the cause. Over the past few years she has held two successful fundraising balls and she is also among an elite group of people who have won a Paul Newman Foundation Award. This Spring, Fiona is hosting a fashion show in Adelaide – **Catwalk for a Cure**. Sunday, 12 September, 2–5pm, at Casablaba, 12 Leigh Street, Adelaide. \$25 entrance tickets can be booked online at: [www.gofundraise.com.au/CatwalkForACure](http://www.gofundraise.com.au/CatwalkForACure)

New to fundraising, Grace Holzhauser from Townsville is setting out to make MS just a memory. She has lofty ambitions to progress upwards to hosting a gala dinner after the success of her initial events earlier this year. Grace said 'Because of F5m's encouragement and support it gave me so much inspiration to do my first major fundraising. I have not done any fundraising before, this is the first and I can assure you it won't be the last! ■

## Spring intentions

With the change in season and warmer weather, spring is a great time to revisit our personal goals. Have you considered tying in your personal goals with fundraising for a cure? You could abstain from alcohol, lose weight, get fit, all perfect reasons to **Quit for a Cause**. To start your spring intentions fundraising page please visit [www.quitforacause.com.au](http://www.quitforacause.com.au) ■

## MyStery Ball Success

The second successful MyStery Ball was held at GPO in Martin Place in May raising over \$24,000. This supportive group of friends worked tirelessly to make this glamorous occasion a success for MS research funding. As you can see from the photos above, the beautiful people certainly dressed mysteriously! ■

## Throw the Book at MS

Throw the Book at MS included two major events this year at Mosman and Paddington in Sydney with over 50 smaller book group gatherings around the country, raising an amazing \$25,000.



Book shops, reading groups and libraries in every state continue to enjoy organising gatherings for book lovers. With questions supplied, it is a very easy format to use for an event. Throw the Book at MS is in its 4th year and in total has raised close to \$70,000.

To find out more about this event, or to host your own Throw the Book at MS event, please visit [www.throwthebookatms.org.au](http://www.throwthebookatms.org.au) ■

## Running for a cure

Hundreds of runners from across Australia recently took up the challenge to run for F5m and MS research in the Run Melbourne and Sydney's City 2 Surf. It was a heartwarming sight to see the sea of green tops running down The Esplanade at Bondi. Combined, both events raised a generous \$42,000.

There are many other running challenges coming up including the **Sydney Running Festival** on Sept 19th and the **Run4Fun** on Nov 7th. If you would like to show your support for F5m in these events please contact Neil on 1300 356 467 and a running fundraising pack will be sent to you. ■



## F5m Facebook Page

All these events and more can be viewed and shared with your friends on our F5m Facebook page (separate to the MSRA page). We encourage everyone to become a fan and use this page to promote their F5m fundraising events. ■

# Walkers and Supporters join M2S

## The Mudgee2Sydney walk in September is attracting a steady number of fantastic supporters.

Joining F5m devotees Katrina Hemingway and Liz Melchior will be friends, work colleagues, supporters and People with MS. The corporate community too is now stepping onboard including **Volkswagen's** offer of two safety and support vehicles for the entire event! See other generous sponsorships (and opportunities) at [www.m2s.org.au](http://www.m2s.org.au)



Among the walkers is Debbie Bird who marks 18 years since she was diagnosed with



LIZ MELCHIOR, KATRINA HEMINGWAY AND DEBBIE BIRD TRAINING FOR THE WALK.

MS and already knows the difference that research can make. 'Back in 1992 there was no treatment that could be offered. It was a matter of getting on with life and hoping for the best. Since then there have been many changes and now, thanks to vital research, there are several drugs which help to reduce the devastating effects of this illness. A cure will only be found through funding research,' she said. Debbie is keen for everyone to join her, Katrina and Liz by donating any amount they can. Visit her fundraising page at [www.m2s.gofundraise.com.au/DebBird](http://www.m2s.gofundraise.com.au/DebBird)



Community groups – including schools and clubs – are registering to join them for the community 6km fun walk or 14km fun run in Mudgee on Sunday 12 September or on the walk (where available). Support drivers are still needed. Other volunteering activities are available so please check out ways you might join in and/or encourage others. Naturally donations are a prime way to acknowledge support.

Visit the [www.m2s.org.au](http://www.m2s.org.au) website to take part in the streets or in spirit! ■



Mail this form or donate online  
[www.msra.org.au](http://www.msra.org.au)  
Donations over \$2 are tax deductible



- My one off tax deductible donation is \$ \_\_\_\_\_
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please charge \$ \_\_\_\_\_ to my credit card per month until notified.
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Card No: \_\_\_\_\_  
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Title: \_\_\_\_\_ First Name: \_\_\_\_\_ Surname: \_\_\_\_\_  
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Suburb: \_\_\_\_\_ Postcode: \_\_\_\_\_  
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Email: \_\_\_\_\_
- Please note here if your donation is made in memory of someone or for a function.  
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