



Milestones, mysteries and MS research

MSRA has made its most significant investment in two high-performing scientists to firmly secure their research efforts in unravelling the mysteries of genetics and neuropathology in MS.

"This unprecedented level of investment is recognition of the progress of MS research in Australia," said Jeremy Wright, Executive Director MSRA. The MSRA commitment of \$970,000 over the next five years will provide the two recipients with the financial security they need to undertake an ambitious MS research agenda.

Dr David Booth from Westmead Millennium Institute (NSW) receives the inaugural MSRA Senior Research Fellowship that will support his MS genetics program, international collaborations and foster a team of talented researchers. Dr Booth was one of the researchers responsible for identifying several of the MS genes now known to play a role in MS susceptibility, and is a member of the Australian and International Genetics Consortium.

Dr John Parratt from the University of Sydney is a rising star of MS neuropathology research and a practising neurologist. Awarded with the Practitioner Fellowship, Dr Parratt said "MSRA has provided me with the chance to bolster my research interests, especially in the neuropathology of MS, whilst maintaining direct contact with patients through my clinical work."

Mr Wright highlighted, "Without clinical fellowships, talented researchers like Dr Parratt would otherwise be lost to clinical practice. His research will accelerate as he focuses on the neuropathology of MS, understanding the early stages of MS lesion formation."

Senior scientists and clinical researchers are the backbone of scientific research. Each plays an important role in investigating important aspects of MS that may lead to better treatments, prevention and a cure. Mr Wright said, "Scientific research is a highly competitive field, with funding grants spanning an average three years, so there is a short period in which researchers have to generate results." This means that research tends to be risk adverse with more ambitious research not undertaken. MSRA is changing all that by backing researchers with a strong track record and commitment to MS research to undertake the projects likely to yield greatest benefit for people with MS.

“ THIS UNPRECEDENTED LEVEL OF INVESTMENT IS RECOGNITION OF THE PROGRESS OF MS RESEARCH IN AUSTRALIA ”



DR JOHN PARRATT (LEFT), PROF BILL CARROLL AND DR DAVID BOOTH (RIGHT) RECEIVING THEIR AWARDS.

This is a major milestone in MSRA's short history. Mr Wright concluded "this investment, and the confidence we have in these researchers will generate results that will translate into better treatments and a cure for people with MS."

MSRA would also like to acknowledge both MS Australia ACT/NSW/VIC and the Penn Foundation for support that has enabled us to fund these Fellowship positions.

For a snapshot of all research MSRA is funding in 2010, please turn to page 5 or visit www.msra.org.au

Oral therapies on trial



Oral treatments have been highly anticipated by neurologists and 2.5 million people with MS worldwide. Oral tablets are not only easy to administer, but reduce restrictions on lifestyle and improve adherence.

Three clinical trials published in *The New England Journal of Medicine* (January 20, 2010) report on the results of two oral therapies, Fingolimod and Cladribine, in the treatment of **Relapsing and Remitting MS**. All three clinical trials indicate that both new oral therapies are at least as effective as existing disease-modifying medications.

MSRA's Scientific Chairman Prof Bill Carroll's editorial, in the same publication, gave details of each of these trials (see article on the MSRA website www.msra.org.au).

"We have learnt from these and other clinical trials that early direct targeting of the immune system offers the best

hope for the prevention of later disability," Prof Carroll said.

Cladribine is given in two or four short courses annually, while fingolimod is taken daily. Both Cladribine and Fingolimod work in different ways to existing medications to reduce inflammation, the key driver of immune injury in MS.

Post-marketing surveillance will track and detect any increase in adverse symptoms. Prof Carroll added, "Clinicians and patients need to evaluate the benefits and risks for each drug. It is integral that we understand the cause of MS. Until then, time will determine the long-term effectiveness of these treatments in delaying irreversible disability." ■



Family fulfils Beth's wish

It is the second anniversary of the launch of the MSRA Brain Bank (MSRABB) and clearly, the word is getting out: more than 900 people with MS have already expressed an interest in donating their brain tissue for MS research and almost 400 people have formally consented. Family members of the 14 donations received so far have found the donation process very smooth.

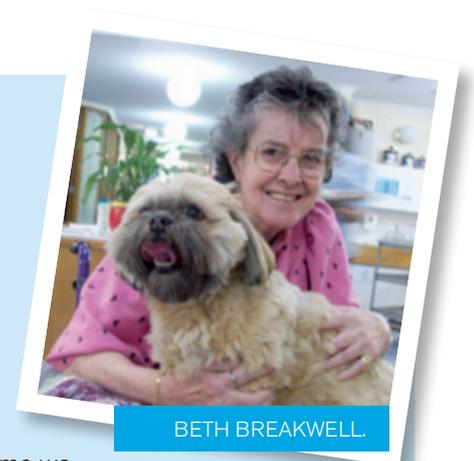
Beryl, known as 'Beth', Breakwell lived with MS for many years and was ahead of her time. When her brother John and sister-in-law, and best friend, Lorraine Breakwell, told her they'd read that a brain bank was being set up for MS research, she said she'd always wanted to donate her brain, and had in fact enquired about it years ago.

"So it wasn't hard for us because it was what she wanted," said Lorraine. "Our family thought it was wonderful that we could help fulfil Beth's wishes."

Lorraine and John got the paperwork, helped her fill it in, and let Beth's doctors and nursing home know her instructions.

"It was made easy. The forms all explain who gets copies, and the funeral directors transported Beth's body from Canberra to Sydney for the procedure."

When Beth died, the Breakwells notified the MSRABB Coordinator immediately and told the hospital she was a brain donor.



BETH BREAKWELL.

"When we got in touch with the funeral home we explained Beth's wishes and told the hospital and Brain Bank Coordinator which funeral home we were using. The Bank handled it all from there."

It is vital to notify the Brain Bank Coordinator in your state when a donor's death occurs or is imminent. The MSRABB works closely with the Australian Brain Bank Network (ABBN) to carry out brain donations as quickly as possible. Tissues preserved within 24 hours of death will enable the best research to be done. Although they did not manage the procedure, Lorraine and John were not left wondering what was happening.

"The funeral directors kept us informed as to when Beth's body was going to Sydney and when she would be back," said Lorraine. "There was no delay for the funeral and no cost to us. It was all very well managed."

Researchers around the world, who are investigating the cause of MS and developing better diagnosis and treatment of the disease, depend entirely on the generosity of donors like Beth to make the vital gift of brain donation after death. Donated brains and other consented tissues are treated with the greatest care and respect, and every brain really does help us move closer to a cure.

For more information, please call 1300 672 265 or visit www.msbrainbank.org.au ■

Angels, artists and other committees from heaven



MSRA is very fortunate to have the support of a most committed team of community fundraisers. Many belong to a dynamic group called Foundation 5 Million (F5m) named after their goal to raise \$5 million – and they have already raised over \$3 million!

F5m fundraising events contribute to the Australian MS research effort. Without this generous community support, the following research may not have been possible.

Dr Pamela McCombe, at the Royal Brisbane and Women's Hospital, is studying the immune system changes that occur during pregnancy. In many patients with MS, disease activity is reduced during pregnancy and increased after pregnancy. By studying the effects of pregnancy in mice with a disease similar to MS, it may be possible to reproduce these as a therapy for MS. This project has received funds from Canapés and Canvas, a Brisbane committee including women with MS.



The Ian Ballard Travelling Fellowship is named after the founder of F5m. The 2010 recipient is **A/Prof Fary Khan**, Director of the Rehabilitation Medicine Department at the Royal Melbourne Hospital. The Fellowship allows A/Prof Khan to draw from international experts to innovate and improve patient care of people who are vulnerable and have complex needs in our community.



The MSRA Proteomics Collaboration, led by **Prof Shaun McColl**, is using state-of-the-art technologies and human tissue to identify changes to proteins that may be involved in development of MS.



Prof McColl highlighted "the insights we generate will help evaluate prognosis of patients, guide their treatment and provide novel therapeutic approaches," he said. This is a national collaboration, funded in partnership with the Australian Research Council and Adelaide-based F5m supporters Fiona DuRieu and Deb Landau.

Dr Judith Greer at the University of Queensland is investigating why lesions in specific areas of the brain develop, and will look at the role played by a particular molecule called PLP. The research may generate targeted treatments to specifically prevent damage to these areas of the brain, without causing unwanted side-effects.



Laura Gianni, a PhD student at the University of Melbourne, is training in highly specialised proteomics techniques to identify biomarkers that occur in MS. Biomarkers are biological substances (e.g. proteins) that can be used for diagnosis, measuring disease progression or the effects of treatment. Laura's passion comes from a personal connection to MS through her father, Aldo, who was diagnosed with the disease in 2002. Both Dr Greer and Laura are directly supported through the MS Angels, a group of Sydney-based business women.



The Trish MS Research Foundation and Charity Works for MS are also dedicated F5m supporters who have directed significant funds to a number of research projects (research outlines to be provided in the next newsletter).

For the full list visit www.F5m.org.au ■

QUIT FOR



Need encouragement to keep those 2010 resolutions? Or do you wish to quit a bad habit once and for all? If so jump online and register at www.quitforms.com.au

Quit for MS is part of the Quit for a Cause online fundraising campaign established by GoFundraise. It will run until the end of April, with all Quit for MS proceeds going to F5m and MS research.

Register to quit anything, from smoking or drinking to swearing or even back seat driving! Ask your family and friends to show support by sponsoring you. It might just be the motivation you need!

Log on to www.quitforms.com.au to register and see what some of our other quitters have given up for a good cause. ■



It's all about people power!

In December, 332 people in Wollongong took part in the Savvy Health and Fitness 'Survivor VII' boot camp. This week-long event has already raised over \$37,000 for F5m, with more to come.

One Savvy Survivor was Derek Crow (pictured above top left), proprietor of The Green Slip King. Derek became involved when his daughter was diagnosed with MS in October 2008. He sponsored his son Daniel in the event for \$10,000. This will be matched dollar for dollar by Daniel's employer BT Financial Group. Participants from BHP Billiton are also having their contributions matched. ■

The March marathons!

Cycling, paddling, running, walking and sweating: these are the ways some exceptional supporters of F5m will be harnessing their own power to cross almost 2,000km of Australian terrain to raise more funds for MS research this year. March is a particularly active month for F5m.

Starting on the 7 March, Tim Charleson and 14 of his colleagues from John Holland Construction will conquer the Three Peaks Ascent. Riders will be taking on this one day cycling event, traversing 230km of Victoria's spectacular Alpine region while raising funds for F5m. For more information, head to www.F5m.org.au

On the 10 March a group of cyclists from MLC Risk Specialist Network are holding a Risk Ride for MS research. Teams are involved from Aviva, AIA and Wealthfarm Financial Planning. This challenging and rewarding charity cycling event covers 400km over four days along the Great Ocean

Road – Mt Gambier to Lorne. MS research was chosen as their dedicated charity because friends and family of team members, clients and advisers have first-hand experience with MS and are passionate about finding a cure. To support them on their journey visit www.F5m.org.au

From 14 – 24 March, Cory Pearce, his family and friends hope their 1,000kms in 10 days will raise \$100,000 for MS research. They will paddle, cycle and hike through beautiful regional Victoria. For more details on participation or sponsorship, visit www.ms1000.org.au

From 16 – 27 April will see two mates from NAB, Phil Salter and John McKenzie, walk 250km from Newcastle to Sydney. Both Phil and John are inspired supporters of MS research funding as they work closely with two colleagues with MS. ■

Lunching – for a cause

Last November F5m newcomer Kelly Lopez, with the help of family and friends, held an MS 'Long Lunch' fundraiser at Castlemola in Leichhardt.

The occasion was a lot of fun, and close to 100 guests found it informative and inspirational. Kelly herself knew little about MS until she was diagnosed in 2008 at the age of 24. Once the initial shock subsided, she was determined to educate others about the disease and its increasing incidence. A huge raffle and auction was held raising \$12,295 which exceeded all expectations. A fantastic effort from all involved! ■



Coming up

- Exciting news on the South East Asia front: Katie Ballard's next Beyond Long Tan Tour is scheduled to leave in April. Beyond Long Tan specialises in tours to Vietnam which includes the "living history" of Australia's involvement in the Vietnam War. Each group will travel with a Vietnam Veteran. \$100 per person will be donated to F5m. If you have been thinking about travelling to Vietnam or would like more information please visit www.beyondlongtan.com.au
- Prefer dressing up? The next Mystery Ball cocktail function is taking place on May 1st at the GPO in Martin Place, Sydney. Four years ago



this event started as a backyard BBQ and has now developed into a Masquerade ball expecting to reach 600 people. Don't miss this opportunity to dress up and dance the night away. For more information visit www.themystery.org.au

- Here's an easy fundraising choice for any F5mer looking for an idea this year. 'Throw the Book at MS' is a trivia night with all questions based on books and authors. All you need do is email register@throwthebookatms.org.au or call (02) 9267 2711 or visit www.throwthebookatms.org.au and we will send you the format for the evening. Now in its 4th year, this fun event has proved popular with many repeat visitors (book groups or solo readers).

SNAPSHOT of MSRA-funded research activity starting in 2010

Genetics & Epidemiology

Identifying the triggers for MS



Developing better treatments

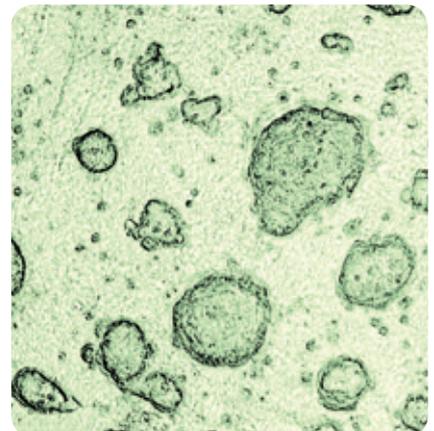
In a nation-wide study:

- **NMO** A/Prof Simon Broadley is leading a collaboration to measure the prevalence and incidence of a rare variant of MS called neuromyeliticoptica (NMO).
- **MSRA Prevention Trial** is a national collaboration to measure the effects of vitamin D in people susceptible to MS.

At the Westmead Millennium Institute

- Dr David Booth will lead a research group in refining MS genetic associations.

A cure for MS via repair or regeneration of cells



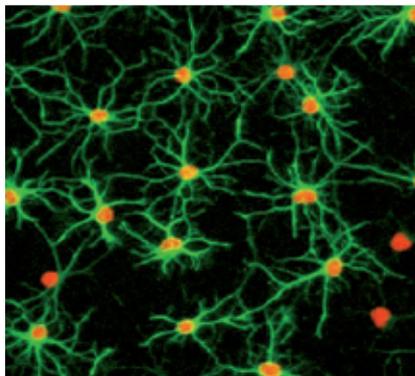
Neurobiology

At the University of Melbourne/ Florey Neuroscience Institutes

- Scott Kolbe is a Research Fellow determining if MRI techniques can predict permanent vision loss in MS after optic neuritis.

At the University of Sydney

- Dr John Parratt will continue his work in the neuropathology of MS, working closely with Dr John Prineas.



At the University of Melbourne

- Dr Ben Emery is unravelling the events and potential 'master gene' that control myelination in the brain and spinal cord.

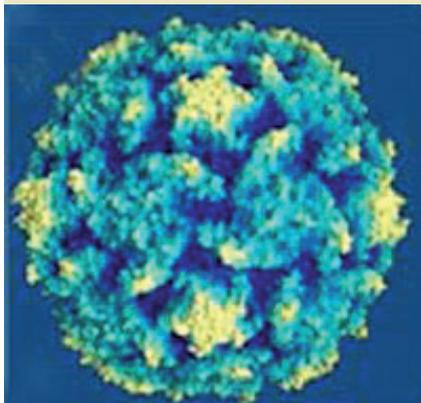
At the University of Adelaide, Monash University, Sir Charles Gairdner Hospital and the University of Queensland

- Prof Shaun McColl leads proteomics research involving a collaboration to find the proteins that cause MS.

Immunology & Virology

At the University of Queensland

- Prof Michael Pender continues his work to determine the role of EBV in the development of MS, and the potential for treatment.



At the University of Melbourne/ Florey Neuroscience Institutes

- Dr Helmut Butzkueven is interrogating specific mechanisms that cause brain and spinal damage in MS.

At the University of Queensland

- Dr Judith Greer's work will identify why lesions occur where they do in MS.

At the University of Adelaide

- Dr Iain Comerford is a Research Fellow trying to understand the role of white blood cell signalling in MS.

At The Children's Hospital at Westmead (NSW)

- Dr Fabienne Brilot-Turville is beginning to identify the earliest immune responses that work against the brain in children who develop MS.



Social & Applied Research



At the University of La Trobe

- Dr Sophie Hill is leading a multidisciplinary team to develop high quality information and tools to help PwMS manage their health.

At the University of Melbourne

- A/Prof Fary Khan, through the Ian Ballard Travelling Fellowship, will meet with world experts in MS research and management, to learn new techniques that can be brought back and implemented in Australia.



Making a difference with a bequest

When the late John Stringer was diagnosed with Primary-Progressive MS in 2002 his family found it 'almost inconceivable' that the cause of MS was not known and there was virtually no treatment for his form of the disease.

John was unlucky to have a very aggressive form of this debilitating disease which caused a very rapid decline and he died just six years later.

"Research into MS was John's wish," said his father David Stringer, who believes medical progress in auto-immune diseases lags far behind other diseases and that research into MS needs a huge boost.

Both David and his wife Carmel have given meaning to John's wish and have generously pledged half of their estate to MS Research Australia. This promise honours John's memory. His wife Michelle, who cared for him, and the rest of his family are supportive of this heartfelt instruction. It also supports John's own decision to donate his own brain for further research, via the MSRA Brain Bank.

"With the current progress in genetics – and stem cell research in particular – it is clear that the cause, treatment and cure for MS are attainable," David said.

John's family believes MSRA provides the focus necessary to unlock the mystery of MS.

"Supporting research facilitated by MSRA seemed by far the best way of giving some real meaning to John's wishes, which my wife and I both shared."

"It's of primary importance to me that the disease that took the young man – who was my son, best friend and golf buddy – in the prime of his life, be beaten. We will do all we can so that others do not have to go through what he did and what we did."

John, who was a nurse at Melbourne's Lort Smith Animal Hospital, is survived by his father and sister, Sharee, who will be executor of the family estate in future.

For information on bequests to MSRA to fund research aimed at solving MS, please go to www.msra/donate/Bequest.php or phone 1300 356 467. ■



JOHN STRINGER (RIGHT) WITH HIS FATHER DAVID.



Mail this form or donate online
www.msra.org.au
Donations over \$2 are tax deductible



- My tax deductible donation is \$ _____
- Please debit my: Visa Card Mastercard Amex
- Card No: _____
- Exp: ____/____ Signature: _____
- 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.
- Title: _____ First Name: _____
- Surname: _____
- Address: _____
- _____ 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.

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