



What do people with MS need? – new report paints national picture

A study commissioned by MSRA in consultation with the state MS organisations, shows that many people with MS are still struggling to obtain the equipment and home modifications they need to live independently.

The study, conducted by Prof Marita McCabe and her colleagues at Deakin University, Melbourne, has provided a thorough analysis of what people with MS need and which of those needs remain unmet.

'The National MS Needs Analysis Report will provide a powerful tool which will assist MS Australia (MSA) in its goal to reduce the impact of MS on the lives of individuals and their families,' said Mr Rob Hubbard, MSA President.

The National MS Needs Analysis Report will be launched on 3 December to coincide with the International Day of Disability. It will also be available to view on www.msra.org.au. Over 2,900 people with MS from all over Australia participated in the Needs Survey that underpins the report.

The survey, designed by Prof McCabe, was implemented through the long-running MSRA research platform, the Australian MS Longitudinal Study (AMSLS), managed by Dr Rex Simmons at Canberra Hospital. It represents a sample of more than 12% of the total Australian MS population. A previous study has validated the demographic spread of the AMSLS participants as an accurate representation of MS in Australia.

The Report will enable MSA and the state MS organisations to develop a full and objective picture of the current needs of people with MS. It will provide the background information necessary to plan the provision of services in a changing future with a growing number of medications and the planned National Disability Insurance Scheme.

The Report provides a detailed analysis of the needs of people with MS in the categories of information, employment, transport, psychological services, peer support, equipment, other support services and respite.

In addition to problems with equipment and home modifications, access and reliability of transport was also highlighted as a significant issue. More assistance is required to manage MS in the workplace and navigate the complex system of benefits. Financial advice also emerged



PROF MARITA McCABE AT DEAKIN UNIVERSITY CONDUCTED THE NEEDS ANALYSIS.

as a major area of unmet need for people with MS, particularly regarding their superannuation.

For people newly diagnosed with MS, psychological support is identified as most important. Peer support is also highly valued by all people with MS, but a greater variety in the types and use of peer support groups is needed.

People living in rural and remote regions experience the greatest dissatisfaction with the availability of services, underlining the need for a new approach to connecting with people with MS outside of metropolitan areas.

'We are grateful to everyone who took the time to participate in this study and who helped to make it such a comprehensive report that will inform the provision of services and target research into the future,' said Jeremy Wright, Chief Executive of MSRA. ■

Congratulations to MS researchers – \$3.5 million in new funding from NHMRC

MS research will benefit from over \$3.5 million of the funding announced in October from the National Health and Medical Research Council (NHMRC). It awarded a total of \$652 million in new funding for 1,141 new grants to commence in 2013.

With great pride we share the news that researchers previously funded by MSRA are among the beneficiaries.

The funding covers researchers from around the country, including a large grant for a national collaborative initiative looking at the role of environmental and genetic factors in progression of MS, led by Prof Bruce Taylor at the Menzies Research Institute Tasmania. This study involves a team of MSRA funded researchers in Australia and New Zealand.

To read more about this project, please see article on page 6.

A/Prof David Booth and Prof Graeme Stewart and their team from Westmead Millennium Institute received two project grants, together worth \$1.1 million, to look at specific genetic factors in MS. Both hold current MSRA research grants and their NHMRC projects extend on the current knowledge about genetic susceptibility to MS developed by the MSRA ANZGene Platform. The projects will investigate the role that genes involved in vitamin D metabolism play in susceptibility to MS, as well as how the IL7R gene may affect responses to interferon treatment.

Dr Suzanne Hodgkinson, a neurologist at Liverpool Hospital and MS researcher at the University of NSW,

received a \$340,000 NHMRC grant to investigate whether regulatory immune cells can be deliberately activated to control the damaging inflammation in MS. This grant will add to her earlier work looking at immune regulatory mechanisms.

A number of highly competitive NHMRC fellowships have also been awarded to up-and-coming MS researchers. Dr Scott Kolbe, University of Melbourne, received an Early Career Fellowship worth close to \$300,000. Dr Kolbe will continue his previously MSRA funded work on optic neuritis; examining the ability of neurons in the visual pathway to rewire and restore function in MS.

Dr David Brown, University of NSW, and Dr Kaylene Young, University of Tasmania, both currently hold MSRA project grants, received Career Development Fellowships worth \$440,000 from the NHMRC. Dr Brown's research will examine mechanisms of neuroinflammation. Dr Young will investigate the potential of new cells added to the nervous system to generate repair.

'We would like to warmly congratulate all those who were awarded NHMRC funding for 2013,' said Jeremy Wright, Chief Executive of MSRA. 'Once again we see how valuable the 'multiplier' effect can be where a smaller investment from generous donors to MSRA can get the preliminary data needed to support an application for a larger amount of funding from the government. We are pleased to see our research model at work.' ■

MS Prevention trial underway

Earlier this year MSRA was delighted to announce that sufficient funding had been secured to commence the PrevANZ vitamin D MS prevention trial, with a substantial grant from the MS Society of WA.

Preparations have progressed exceptionally well and clinical sites around Australia and New Zealand are now ready to begin enrolling. The PrevANZ trial was officially launched by The Hon Julie Collins MP in Hobart in October and received a great deal of attention in the media and community.

'Our colleagues in the state MS organisations have made a significant contribution to this trial, particularly WA, QLD and TAS,' said Jeremy Wright, CEO of MSRA. 'We are also grateful for the support of the Trish MS Research Foundation, Foundation 5 Million+ and the John T Reid Charitable Trusts.'

'We can enrol a statistically significant cohort of 160 people with this funding,' said Mr Wright. 'Although for a fully conclusive trial, we do need a further \$1 million.'

This 'gold-standard' randomised, placebo controlled trial will determine the efficacy and safety of oral vitamin D supplementation to prevent MS in people at high risk of developing the condition. Enrolment will occur through neurologists. People already diagnosed with MS will not be eligible for the trial, but if they have concerns about their vitamin D status, they should discuss this with their GP or neurologist.

For further information or to make a donation visit www.msra.org.au/prevanz ■



■ THE HON JULIE COLLINS MP.

Kiss Goodbye to MS extreme style

With the New Year almost in sight, we thought we'd provide you with some inspiration on making a resolution that could improve your well-being, spread positivity AND directly support MS research and support services in Australia..... all of this and more can be achieved when you decide to join in the fun and Kiss Goodbye to MS!

Check out these amazing fundraisers who are all going to extreme lengths to support Kiss Goodbye to MS in 2013 and perhaps have a think about how you could make a radical red-lipped resolution and help us smash our \$1 million fundraising target next year. ■



Dominique to drive MS round the bend

Glamorous Dom Chaleyzer can be seen most weekends whizzing around the track in 'Big Red', her 1965 Alfa Romeo, which is now fabulously branded with Kiss Goodbye to MS decals.

Dom grew up with first-hand experience of MS as her mum, Lindy, was diagnosed when Dom was just five years old. More recently, Dom's best friend, Roula, has also been diagnosed. The young racer has now made it her mission to tackle this horrible disease head on. Dom is already breaking down barriers by being the first female to compete in a variety of historic races – so we can rely on her to break down the barriers and Kiss Goodbye to MS! ■



Mow-down MS says Megan

Mum-of-three Megan Healey may have MS, but MS doesn't have her – and to prove it, she's going to drive a new Ferris ride-on mower, from Melbourne to Sydney in May 2013!



Megan, who has lived with MS for many years, wants to show that even if you have a disability, you can accomplish great things if you put your mind to it. She also wants to raise funds for research into the cause, cure and treatment of MS and to provide support services to people living with the disease. ■

Gilli's Tour of Tassie

Gilli Barnard is planning a fantastic new year's resolution for January 2013 – she is kissing goodbye to her everyday commitments and heading off on an epic tour of Tasmania, all the while raising funds and awareness for Kiss Goodbye to MS.

Gilli, who was diagnosed with MS 35 years ago, is an amazing Ambassador for the campaign and has branded her van, her mobility scooter and even herself with the Kiss Goodbye logo! Gilli has already started making friends in high places and is pictured here with local politician The Hon Julie Collins MP. ■



To find out more about these fantastic fundraisers visit: www.kissgoodbyetoms.org/news

The 'Little' Big Swim

We are delighted that this year, Whale Beach Surf Life Saving Club, the organisers of the Big Swim, a 2.5km ocean swim from Sydney's Palm Beach to Whale Beach, have selected Kiss Goodbye to MS as their official charity partner.

They are even instituting a special 1km 'Little' Big Swim so beginners can participate. The event will take place on Sunday 27 January 2013 and all participants are encouraged to raise funds for Kiss Goodbye to MS AND to take part in a photo opportunity for a World Record attempt of the most swimmers wearing red lipstick (guys included)! ■

**To register as a fundraiser go to www.kissgoodbyetoms.org
For swim information and entry go to www.thebigswim.org.au**

Gaining insights at international Brain Banks

Dr Antony Harding, the MSRA Brain Bank Manager, has travelled to two international Brain Banks to observe methods and exchange knowledge.

Recently appointed to this role, Dr Harding visited the UK Brain Bank in London and the New York Brain Bank at Columbia University. This allowed an exchange of knowledge about brain collection and preservation methods.

The UK MS Brain Bank has been running for 14 years and the New York Brain Bank for over 11 years. Both are internationally recognised as leaders in neurological tissue collection and storage. 'It is great to be able to meet with other experts in the field to see what we can learn for our own facility,' said Dr Harding. 'With our new operation being set up in Sydney, it was perfect timing to revise and improve our techniques.'

During his visit, Dr Harding was able to witness brain donations at both facilities and compare the international procedures with those used here.

Previously a neurological researcher, Dr Harding is one of the leading tissue bank experts in Australia. He served as the National Coordinator of the Australian Brain Donor Programs until 2011 and has been both secretary and treasurer for the Australia and New Zealand Society for Neuropathology. He has worked specifically with brain donations for over seven years and MSRA is thrilled to be



■ DR ANTONY HARDING, MSRA BRAIN BANK MANAGER.

able to bring Dr Harding's experience to the MSRA Brain Bank.

If you wish to register as a brain and tissue donor please phone 1300 672 265, email msrabrainbank@msra.org.au or register online at www.msbrainbank.org.au to receive your consent pack. ■



Government website boosts access to clinical trials

The federal government has established a new website to provide Australians with information and boost participation in clinical trials.

The website, www.australianclinicaltrials.gov.au was launched in October by the Hon Tanya Plibersek MP, Minister for Health, and the Hon Greg Combet MP, Minister for Innovation and Industry.

Developed by the National Health and Medical Research Council (NHMRC) as a result of recommendations from the Clinical Trials Action Group, it is a collaboration of government, industry and consumer representatives.

Ms Plibersek said, 'Clinical trials give tens of thousands of patients access to new and innovative treatments and play a vital part in the fight against disease.'

The website aims to make it easier for patients to understand and access clinical trials. It includes information on what's involved in participating in a clinical trial, how and why clinical trials are designed the way they are, the regulations surrounding clinical trials and what questions to ask if you're considering participating in a trial. The website also includes a searchable listing of clinical trials networks and registers to help people find clinical trials.

For a full listing of MS clinical trials available in Australia and New Zealand please visit the MSRA Clinical Trials Network website at www.msclinicaltrials.org.au ■



F5m+ = \$6 million in 6 years

Ian Ballard, our F5m founder, had a dream. And you, F5m+ supporters, have lived it and breathed it. In fact, in six years we exceeded the \$5 million and a total well over \$6 million has now been raised. From parties to trivia nights, from marathons to garage sales – this very grand total was achieved in six years. Pat yourselves on the back and know that MS research has been endowed. Ian's dream that future generations will benefit from this is coming true (see page 2 for just one example).

Bikini idea helps to top fundraising effort

Say hello to a new F5mer, Ed Williams. He recently ran the Blackmores Sydney half marathon and became the event's top individual fundraiser as well as setting a personal best time for his fantastic effort. All at F5m+ salute him for this effort. Oh, did we mention, he ran the race in a bikini as a dare.

Back in May, Ed decided he really wanted to participate in this event and knew he could use it as an opportunity to fundraise. He discussed this with his parents, Paul and Cindy Williams and between them the bikini idea arose. They knew that people who dare to do something silly often increase their donations. Ed's employer, Westpac, have been fantastic too, 'They will match my personal donation of \$6,320. They also did a great article in the internal newsletter encouraging staff donations. In all, it's been a great experience,' said Ed who wanted to find a charity that conducts research into MS as his mum, Cindy, has lived with it for 30 years. So F5m+ was chosen and we are most thankful that it was.

'I really liked the people we met at MS Research Australia and Foundation 5 Million Plus. They were able to clearly state where the money goes. Also, it was not only the research that impressed me but how they are supported mostly by people with MS and their families,' said Ed. 'In fact my family have been embraced very quickly and were among those who attended the Trish MS Research Foundation ball in September.'

Once again, it is the work and results of people like Ed and his family that allow us to keep up the good work so that research will continue to find better treatments, a cure or even prevent MS. ■



ED WILLIAMS WITH HIS PARENTS CINDY AND PAUL AFTER HIS RACE. SEE ABOVE ABOUT THE BIKINI!

F5m+ family multiplies...

Hello supporters in Melbourne: F5m+ held a meeting recently in the Garden City and it was well-attended by fundraisers and friends. It seems there is growing interest in our dynamic organisation.

Though small in size, it is large in impact – the recent Charityworks 4 MS Ball raised over \$200,000 along with other events in VIC. The people, the goals and the way F5m+ embraces all kinds of fundraising ideas have been welcomed by many across the nation.

Everyone agreed it was time to look at perhaps starting a local Melbourne based group. We invite expressions of interest or comment from people with MS, their families, friends and workmates. Give us a shout if you want to join the Melbourne F5m+ group and be involved with forming a bigger and better team to support the F5m+ mission in funding MS research. Please email your interest to info@F5m.org.au ■



■ F5M+ IN THE GARDEN STATE!

Stop Press!! We just had contact from a Canberra F5mer who asked the same question. Anyone in Canberra interested in talking about doing an event or joining the F5m+ group, please email info@F5m.org.au

... and trivia! How do you practice trivia? Actually you can't so you may as well pencil in Saturday 16 February at the Mosman Community Centre, NSW in your diary and hope they have questions you like! Sydney based F5m+ family members visit www.F5mplus.org.au to find out more.....

Nearly \$1M in funding for AusImmune Project



■ PROF BRUCE TAYLOR.

The largest MS-related research grant for 2013, announced by the National Health & Medical Research Council (NHMRC) in October, will go to research to continue the work of the AusImmune Project. The grant is worth in excess of \$945,000 and will run for five years.

The project will be led by Prof Bruce Taylor from the Menzies Research Institute Tasmania with a consortium of previously MSRA-funded researchers from around Australia.

It will look at the role of environmental and genetic factors in progression of MS and continue to follow the cohort of people built up during the AusImmune study which commenced in 2003 with funding from the USA National MS Society and MSRA. The study investigated the role of environmental factors, viral infections, chemical exposures, diet and genetic factors in the development of first demyelinating events (FDEs), a frequent precursor to MS.

'We have a number of highly valuable resources from this population gathered over time which will shed light on the long term risk factors and outcomes for people with MS,' said Prof Taylor.

'The AusImmune and AusLong studies have been considerable undertakings and MSRA is very pleased to have been able to support AusImmune at its outset,' said Jeremy Wright, Chief Executive of MSRA. 'It generated a considerable amount of data on the risk factors for MS, including the role of vitamin D deficiency in the development of MS. We would like to congratulate all involved.' ■

MSRA Partners



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