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 MS
RESEARCH
AUSTRALIA


Disclosing a diagnosis of MS in the workplace may improve job retention

Unemployment rates for people with MS are disproportionately high in comparison to other chronic diseases. Australian researchers have now shown that disclosing a diagnosis of MS in the workplace is, on average, associated with greater employment retention. Results will be published shortly in the *Multiple Sclerosis Journal*.

Drs Pieter Van Dijk and Andrea Kirk-Brown from the Department of Management, Monash University, received an MS Research Australia incubator grant in 2012 to examine psychological issues in the workplace. They collaborated with Dr Rex Simmons from Canberra Hospital to use the MS Research Australia-funded Australian MS Longitudinal Study (AMSLS) to examine the role of disclosure of diagnosis in employment retention for people with MS.

A self-report questionnaire on current employment status, demographics and disability level was completed by 2144

AMSLS participants annually over a three-year period commencing in 2010. Participants who were working for an employer were asked if, and when, they had disclosed their diagnosis of MS to their employer. The data was analysed to investigate the factors leading to disclosure. The relationship between disclosure and employment status and duration was also examined.

Contrary to what many people may expect, results showed that disclosure of an MS diagnosis to an employer increased job retention. One factor leading to disclosure of diagnosis was severity of disability. However, employees who disclosed their diagnosis were more likely to be employed, and more likely to be employed for longer periods of time, even after taking level of disability into account.

Results from the study suggest that after disclosure, employees may receive more assistance with workplace accommodations, social support and

possibly more effective symptom management than non-disclosing employees. Future research will help determine these aspects. Previous research has shown that symptom management in the workplace is key to maintaining employment for people with MS.

This unique study has uncovered some interesting results. 'While everyone's situation is different, these findings provide encouraging information for employees with MS and may lead to people with MS reassessing their workplace situations,' said Dr Kirk-Brown, 'it also has important implications for vocational rehabilitation providers working with clients with MS'. ■

Please note these findings represent a statistical analysis of a large group of people with MS. Individuals should consider their own personal circumstances when considering whether to disclose their diagnosis to an employer. State MS Societies can provide resources to assist with this decision. Please contact your state MS Society for more information.

A word from our Chief Executive Officer

MS Research Australia has had a busy and exciting few months, with recent scientific discoveries, Commonwealth grant success for MS researchers, the listing of two oral MS medications onto the Pharmaceutical Benefits Scheme (PBS), our 2014 research grant round and also preparations for our upcoming Progress in MS Research Conference and Public Lecture.

It is your support, the dedication of the MS researchers and the team at

MS Research Australia that continue to ensure we can accelerate research to find the cause and cure of MS.

The team at MS Research Australia might be relatively small but with the great breadth of expertise, skills and dedication found across the group we ensure that the significant majority of all donated funds go straight into the MS research where it is most needed. Over the upcoming issues of Next I will introduce you to all of our MS Research Australia staff members. ■



DR MATTHEW MILES

Research Development Manager at MS Research Australia

Dr Lisa Melton has a BSc Hons in Biochemistry and Physiology from the University of Sheffield and a PhD in Neuroscience from the University of Newcastle-Upon-Tyne, UK. Following her PhD she completed post-doctoral research at University College, and King's College London, in the areas of development and regeneration of the peripheral nervous system. After a move to Sydney Dr Melton took up a role as Science Communication Officer at the Children's Medical Research

Institute, contributing to the public communication of the Institute's research, before joining the MS Research Australia team in February 2011.

'At MS Research Australia my role is to coordinate the national collaborations, or research platforms, supported by Multiple Sclerosis Research Australia and also, with my colleagues, communicate the amazing progress in Australian and international MS research to the MS community,' says Dr Melton. 'Already in my time working here, I have seen major changes in the treatments available for people with MS with more in the pipeline, and many areas of MS research are reaching really promising stages.'

'While I loved my time at the laboratory bench, I really feel that I have found my niche in my current role. It is a very special position to be in, to work alongside Australian MS researchers and neurologists and support their efforts. I have a great curiosity and passion for research, so being able to contribute my skills in the fight against MS is a great privilege.'

'My PhD research was into the role that inflammation plays in the progression of Alzheimer's disease, so I feel that I have almost come full circle in the work that I have done and the experience that I have gained - neuroinflammation, repair and regeneration of the nervous system, genetics and molecular biology - I can draw on all of this to help me in my role at MS Research Australia.'

'I also work closely with my colleagues in the MS societies around the country to consult with them and coordinate their input into a range of social and applied research projects that we administer. I have learnt a great deal from these colleagues about the challenges of living with MS, and of course the people with MS that I work alongside provide daily inspiration.' ■



DR LISA MELTON

New Australian research uncovers links between genetics, vitamin D and response to treatment

Recent Australian research conducted as part of the international effort, identified 48 previously unknown genes that affect the risk of developing MS, taking the total number to 110. This landmark paper represents the first stage of genetics research, which must then be followed up with analysis to determine 'how' genes act to change individual risk.

The current MS Research Australia Senior Research Fellow A/Professor David Booth at the Westmead Millennium Institute and his colleagues around Australia have been extremely busy tackling just this question. Their work has recently culminated in the publication of three papers in top scientific journals.

A/Professor Booth and the team used separate approaches to look at vitamin D genes, the interaction between genetics and treatment response, and to determine if an overall genetic signature can be used to predict the likelihood of MS.

The work has shown that the gene responsible for converting vitamin D to its active form, known as CYP27B1, behaves differently in different types of immune cells, depending which version of the gene is present. In particular, the version of the gene that confers MS risk is underactive in immune cells called tolerogenic dendritic cells, which are the cells that control the action of vitamin D on the immune system. The resulting effect appears to be a reduced ability to guard against autoimmune misfire.

The team also revealed how another gene, IL7Ralpha, may play a role in a person's response to treatment. Using immune cells grown in the laboratory which contained different versions of the gene, the researchers showed that the cells responded differently to interferon beta treatment. Cells with the version of the IL7Ralpha gene that confers the highest risk of developing MS showed no response to interferon beta. This implies that correct signalling through the activity of this gene and its pathways is important in both

the risk of developing MS and in the response to treatment with interferon beta. The group is now examining whether this information may be used clinically to assist treatment decisions for people with MS.

In the third project the team looked at the activity of a panel of genes in the blood of people with MS and healthy controls, and confirmed an earlier finding that the activity of these genes in blood represented a predictive 'signature' for MS susceptibility.

In the new study the team have refined this signature to a single gene called RPS6, which had higher activity in people with MS and showed that the gene activity varies by season, matching the monthly UV light index. They also showed that the RPS6 activity was reduced when people were treated with interferon beta. This exciting result means that RPS6 activity could also be used in the future to track the response to interferon beta treatment and assist with treatment choices.

'Work such as this further defines MS susceptibility and helps identify people particularly likely to respond to certain therapies', said A/Professor Booth, 'Testing such possibilities is vital to developing cost effective therapies for autoimmune diseases'. ■



A/PROFESSOR DAVID BOOTH, WESTMEAD
MILLENNIUM INSTITUTE



Phase IV Clinical Trials tracking new medicines

Clinical research does not end with the completion of the phase III clinical trials required for the registration and availability of a new drug by prescription.

Phase IV clinical trials take place after drugs are launched in the market and are designed to gather additional data on areas such as risk minimisation, long-term efficacy and safety or cost-effectiveness of new medications.

One example is the very long term follow-up of patients who participated in the original clinical trials for interferon beta that has provided evidence for the efficacy of these medications in delaying the development of disability, as well as further safety data.

Pregnancy registers may also be established for some medications. Based primarily on animal experiments, several of the newer MS medications are not recommended for women who are pregnant or planning pregnancy, however, pregnancies do sometimes occur. It is very important to gather data on the outcomes for mother and child in these circumstances so that accurate advice and information can be provided to women in the future.

Some medications require patients to be monitored at regular intervals while they are on the drug to help mitigate against the risk of some of the potentially more serious side-effects. Clinical studies help refine these risk-mitigation strategies.

With a number of new MS medications recently becoming available in Australia there are opportunities for Australians with MS to contribute to the further understanding and effective use of these therapies. To view a listing of all clinical trials currently underway in Australia and New Zealand please visit www.mstrials.org.au ■



Can you help us **Kiss Goodbye to MS in 2014?**

Getting involved in fundraising is a great way for people with MS, their friends and families to fight back against MS and provide hope for those affected. The 2014 Kiss Goodbye to MS campaign is coming soon and we need your support to make sure it is bigger and better than ever!

Kiss Goodbye to MS is open to everyone, with participants choosing exactly what they would like to do to raise funds towards MS research.

Earlier this year you might have heard about Kiss Goodbye to MS fundraiser, Megan Healey, who drove a ride-on lawnmower from Melbourne to Sydney (M to S), raising over \$50,000 towards MS research! Megan is a mother of three from the Central Coast, whose mobility is limited due to her MS. She didn't let that stop her fundraising and even became a bit of a celebrity, appearing on Channel 7's Sunrise and Channel 9's the Today Show, whilst in the process of completing her inspiring journey!

We are looking for more fundraisers like Megan to support Kiss Goodbye to MS in 2014 - so if you have an idea for raising funds and awareness do get in touch and we will be delighted to assist you in your efforts.

One aspiring fundraiser who has already committed to support the campaign next year is Katrina Hemingway, whose husband Mike is a person with MS. Katrina and a group

of friends are taking up the challenge to walk the entire width of the UK next September (303km) on Wainwrights Coast2Coast MS Walk. Their aim is to raise over \$150,000 towards MS research. Those with a passion for walking and fundraising are welcome to join them! To find out more visit www.kissgoodbyetoms.org/events.

If these fundraising ideas seem a little daunting to you, don't despair! Any fundraising idea, no matter how big or small, will contribute much needed funds for MS research.

Just recently, two young fundraisers, Alex and Sophie - whose mum, Mel, has MS - chose to fundraise by holding a wear red mufti day at their school. They used Kiss Goodbye to MS posters, balloons and stickers to promote the event and raised over \$1000 towards MS research. In addition, two of the male teachers were so impressed with the kids' effort that they agreed to wear red lipstick to morning assembly to say thank you.

Other successful fundraising ideas range from office morning teas, to girls' nights in, to sausage sizzles, sporting events and gala dinners. The list of possibilities is infinite, with the aim to have lots of fun, whilst raising as much money as possible to help us Kiss Goodbye to MS!

For more information on getting involved, please visit www.kissgoodbyetoms.org ■



▶ YOUNG FUNDRAISERS SOPHIE AND ALEX



▶ WAINWRIGHTS COAST2COAST MS WALK TEAM

☎ 1300 785 717 🌐 www.kissgoodbyetoMS.org 📘 www.facebook.com/kissgoodbyetoMS

Year in review at the **MS Research Australia Brain Bank**



The MS Research Australia Brain Bank is happy to report another great year in operations and generous tissue donations. 2013 brought the total count of people who have pledged to donate their brains to over 770 with over 40 brains collected so far. Brains have been donated from donors in all states of Australia. We would particularly like to thank the family members of the donors who provide permission and assistance to us at such a difficult time.

The MS Research Australia Brain Bank is settling into its new home at the Brain and Mind Research Institute at the University of Sydney and has begun the process of detailed

characterisation of the tissue collected from around Australia. This painstaking characterisation process, which details the number and type of lesions in each brain, is unique to the MS Research Australia Brain Bank and allows the tissue to be used efficiently and effectively in research around Australia. This tissue will be used in 17 separate research projects looking at the process of MS in the human brain and spinal cord.

If you wish to register as a brain and tissue donor please phone **1300 672 265** or register online at www.msbrainbank.org.au ■

Community fundraising makes a \$7 million difference

The F5m+ community fundraisers have raised over \$7 million in seven years. We would like to thank all of the individuals in Australia and overseas who have participated in and hosted a vast array of events, our regular donors and our workplace givers.

As a result F5m+ has been able to allocate \$5.9 million to MS research projects which focus on prevention and finding the cause and cure for MS, which currently affects over 23,000 Australians.

Recently the F5m+ research steering committee, comprised entirely of people with MS, met to allocate the additional funding for research projects starting in 2014. Details will be published early 2014 after the official MS Research Australia grant round announcement is made. ■



▶ BEAU O'BRIEN 1ST PLACE ELITE MALE

Paddle to Battle MS 2014

F5m+ will hit the beach again at Collaroy for the second Paddle to Battle MS event in March 2014.

After the successful 2013 event which raised over \$26,000 for MS research, the organisers are busy planning for 2014, which is set to be even bigger and better.

One such improvement is changing the event to be held over two days; catering for the elite with a technical Stand up Paddle race in and out of the surf of Collaroy Beach, and a family friendly flat water event to be held on the shores of Narrabeen Lake at Jamieson Park, Narrabeen.

The organisers are looking for more sponsorship and volunteer support. For expressions of interest please contact Fionna Guy **0406 040 244** or infopaddletobattlems@gmail.com

To keep up to date with the event details and progress visit www.facebook.com/pages/Paddle-to-Battle-MS/131815040321305 ■



From muddy challenges to tours down under



▶ KATE AULD AT TOUGH MUDDER

The F5m+ fundraisers accept a range of different challenges to support their fundraising efforts from muddy encounters to 154 km bike rides.

Kate Auld from Inverell recently travelled to Sydney to participate in the Tough Mudder challenge. Kate not only completed the obstacle course which was designed by the SAS with ice baths and electric shocks but she raised over \$1,200 for MS research!

Dr Mark Slee, Professor Simon Broadley and A/Professor Helmut Butzkueven, all leading Australian MS Researchers, are so passionate about their work that they not only conduct the research, they put themselves out on a bike to fundraise for MS research. They are riding in the Bupa Challenge Tour, the community ride of the Australian Tour Down Under. To support them on their ride please visit www.everydayhero.com.au/event/MilesForMyelin ■

Spend well this Christmas

Shopping online this Christmas? Don't forget to Spend Well. Simply visit www.spend-well.com and choose MS Research Australia/F5m+. ■



Current and future treatments

'Australian scientists have an incredible track record in treating, preventing and curing disease. The elimination of multiple sclerosis is now in our sights - it is not a matter of if, it is a matter of when' - Professor Graeme Stewart AM.

Twenty years ago when a person was diagnosed with MS, the treatment options were very limited and nothing had been proven to prevent the progression of the disease.

In recent years, cutting-edge MS research has led to increasingly positive outcomes for those affected. The first injectable immunotherapy was released in 1993 and the first oral treatment approved in Australia in 2011. Now, two more oral treatments have been listed on the pharmaceutical benefits scheme, significantly increasing the options available for people with MS.

The progress made in such a short space of time is incredibly impressive and Australian researchers are making a huge contribution in the worldwide effort to solve this disease.

However, there are still people with MS who do not benefit from current treatments, particularly those with progressive forms of the disease. So it is essential we keep up the momentum in MS research until a cure for MS becomes a reality.

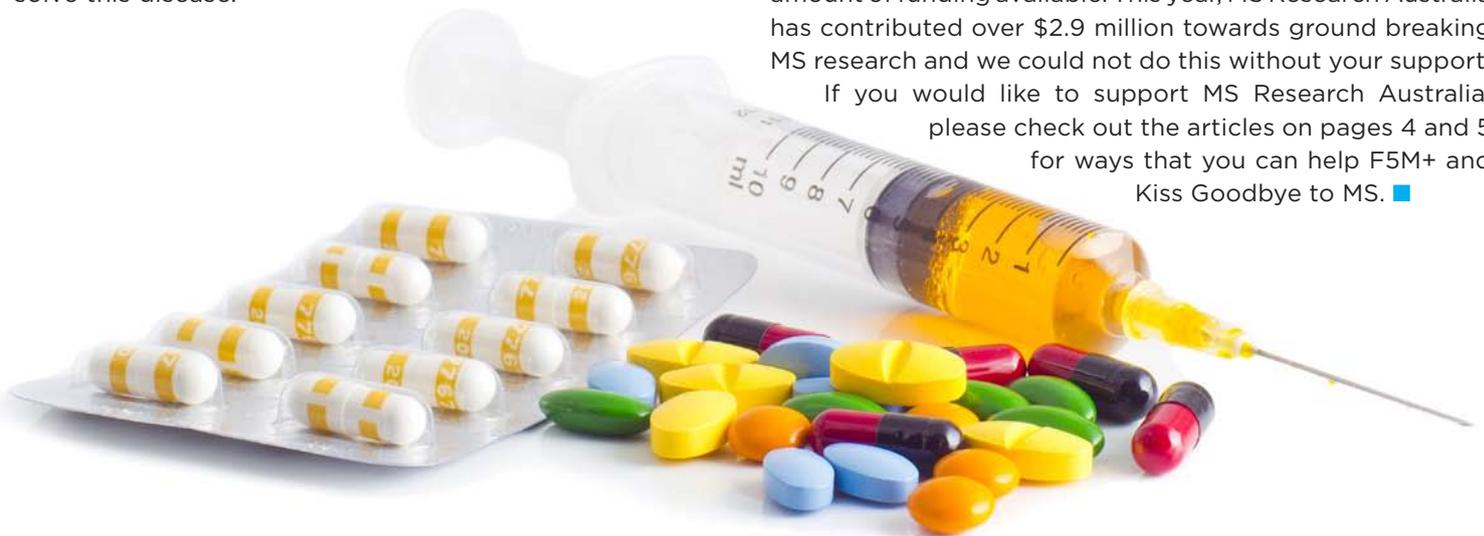
We now know a great deal about the genetics of MS, with a recent international study uncovering another 48 genes implicated in the development of the disease, giving us a total of 110 known MS susceptibility genes. We also know there are environmental factors involved, such as the amount of exposure an individual has to sunlight.

The possibility of repairing damaged myelin and protecting neurons is also within reach with great progress being made in understanding repair mechanisms in the brain.

The more we know about the genetics and biology of MS the better placed we will be to develop highly effective, targeted treatments with fewer side-effects.

MS research is a costly business and is limited by the amount of funding available. This year, MS Research Australia has contributed over \$2.9 million towards ground breaking MS research and we could not do this without your support.

If you would like to support MS Research Australia, please check out the articles on pages 4 and 5 for ways that you can help F5M+ and Kiss Goodbye to MS. ■



Yes, I want to help MS Research Australia

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

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