THE OFFICIAL NEWSLETTER OF MULTIPLE SCLEROSIS RESEARCH AUSTRALIA

MSRA IS THE RESEARCH ARM OF MS AUSTRALIA

Vitamin D and MS - time for evidence

Searching the internet for "vitamin D and MS" will reveal literally over a million hits.

Many people believe that vitamin D supplements can reduce the activity of MS, and different websites recommend that MS patients use vitamin D supplementation. Vitamin D is naturally made in sun-exposed skin, especially in summer, but our increasingly indoor lifestyle and public health campaigns to reduce skin cancer have meant that less of our skin is exposed to the sun, and low vitamin D levels are common, even in this sundrenched country.

As vitamin D is readily available in 1000IU capsules, and is generally safe (with few exceptions), many people with MS take it. It also helps the New Zealand economy as the most common product is made from sheep fat.

However, we don't actually know whether taking vitamin D supplements reduces MS relapses and brain inflammation, and we certainly don't know if the very large doses recommended by some authorities (up to 10,000 IU/day) are in fact any better than lower doses.

In order to address this huge need for evidence, Multiple Sclerosis Research Australia (MSRA) has convened a committee, "PrevANZ", to explore funding and to run a trial

of vitamin D supplementation. It involves providing different doses to people with the earliest signs of relapsing-remitting MS, ie people who have just suffered their first MS-like attack.

The PrevANZ committee are also exploring international collaborations. As a delegate of this committee, Dr Helmet Butzkueven said "I was invited to present to a Scottish summit on vitamin D in MS, held in September this year. Pleasingly, I discovered that a similar trial is planned in the UK and is also awaiting funding decisions. We agreed in principle to share protocols and information, and sincerely hope both projects will be funded."

The Scottish summit on vitamin D in MS was brought about by Ryan McLaughlin, aged 15, from Glasgow. Ryan's mother has MS and he has highlighted the urgent need for improving vitamin D supplementation in Scotland, given the extremely low levels in Scottish people. For more information visit www.shineonscotland.org.uk

The next step is to finalise the resources needed for a comprehensive study. MSRA and PrevANZ is hopeful that this will allow us to generate the evidence required to prove vitamin D is a relevant treatment and a preventive measure for MS.



Beyond the symptoms

Dr Rex Simmons from Canberra University was invited by a leading journal, *Nature Reviews Neurology*, to summarise how effectively people with MS might optimise their quality of life while living with the condition.

Even from early stages, People with MS (PwMS) are vulnerable to disempowerment, poor psychological health and social exclusion including unemployment.

As those with MS and their friends and loved ones are aware, diagnosis leads to uncertainty, not just clinically but also personally and socially. It is vital that PwMS (and their carers) maintain their mental health and avoid depression. This can occur more frequently in MS than in other chronic conditions.

Progress has been made in the forms of psychological services and prescription medications. However, substantial improvements to the mental health, empowerment and quality of life of PwMS require more research.

In his study, Dr Simmons concludes that further progress relies on sociopolitical action, including wider community acceptance of, and government assistance for, the greater



MS AUSTRALIA ADVOCATES AT PARLIAMENT HOUSE CANBERRA.

social inclusion of people with disabilities (particularly participation in paid employment).

It is not only cost-effective to the taxpayer, it may also have profound benefits to the health and quality of life of the recognised participants. PwMS can help achieve such political change by taking part in appropriate, ethical research projects designed to provide the much-needed evidence directly related to government lobbying.

Dr Ben is back in town

With prizes and scholarships already to his credit, Dr Ben Emery is the latest in an impressive line of young researchers funded by the Trish MS Research Foundation.

They are supporting his research work in "Understanding the events that control central nervous system myelination" at Florey Neuroscience Institutes Melbourne.



DR BEN EMERY IN HIS LABORATORY.

The recipient of the Young Investigators Prize at the Progress in MS Research conference in 2004, Dr Emery has returned to Australia from Stanford University in the US, where he resided on a scholarship. It was here, working with Prof Barres, that he discovered a gene that is instrumental in coordinating the myelination process.

Dr Emery said that one of the contributing factors to disease progression in MS is the fact that remyelination (myelin repair) becomes less efficient as the disease progresses.

"I hope that fully understanding this process will lead to develop treatments designed to recreate an environment that promotes remyelination in MS. These treatments could then complement the current therapies that target the immune system," he said

Australian MS research is very fortunate that Dr Emery is back in Australia. He was always drawn to neurobiology research with relevance to human conditions.

"We are lucky to have a person of this calibre devoting his considerable intellect to multiple sclerosis related research. I have every confidence that his work will ultimately be a key factor in improving the lives of people with multiple sclerosis," says Prof Trevor Kilpatrick from the University of Melbourne.

The on-going support of the Trish Foundation continues to play a vital role in MS research in Australia. ■

Promise, Progress and Partners

Great ideas were heard and shared between researchers and donors at recent events hosted by MSRA.

The 'Promise and Progress of MS Research' provided an avenue to thank our Research Partners and, more importantly, allow them to hear about the latest Australian research which they support.

The exclusive events with just over 150 guests in Brisbane, Sydney and Melbourne, provided an opportunity for an update on research by scientists specialising in multiple sclerosis research.

In **Brisbane**, Dr Judith Greer talked about the role of the immune system in MS and her colleague, A/Prof Pamela McCombe on why disease activity appears to be reduced during pregnancy. MSRA scholarship recipient, Jason Mackenzie, talked about areas of the genome potentially containing MS susceptibility genes.

At the **Sydney** event the speakers were A/Prof David Booth, Dr Fiona McKay and Dr Fabienne Brilot Turville (we were lucky to have the latter who filled in at the last minute for Dr John Parratt, whose wife that day gave birth to their son!). A/Prof Booth, based at the Westmead Millennium Institute, explained his ground-breaking work about MS susceptibility. He was recently awarded the inaugural MSRA Senior Research Fellowship.

Research Partners attending the **Melbourne** event heard A/Prof Helmut Butzkueven – just back from a vitamin D conference in Glasgow – from the Florey Neuroscience Institutes, speak about potential neuroprotective treatment to reduce axon damage in MS. Also at the Melbourne event was Dr Ben Emery and Dr Melissa Gresle.



RESEARCH PARTNERS IN SYDNEY HEARD (FROM LEFT)
A/PROF DAVID BOOTH, DR FABIENNE BRILOT TURVILLE AND
DR FIONA MCKAY.

Jeremy Wright, Executive Director of MSRA, facilitated the panel discussion in each city. Guests eagerly asked questions on a variety of aspects of MS research. The highlights will be posted as media clips on www.msra.org.au in the coming weeks.

Being a **Research Partner** of MSRA is an act of generosity and philanthropy. Those involved know that they play a part in funding prevention, cures or better treatments of MS. They are invited to special events and can follow the progress of their 'chosen' scientist or lab group. To find out more about becoming a Research Partner, please visit the website www.msra.org.au or call MSRA on 02 9468 8390.

Strong commitment from new Chairman

Research into multiple sclerosis is something very close to the heart of MSRA's new Chairman, Paul Murnane.

With a background in financial services and management, and with a family connection to the insidious disease, there was no question as to the level of involvement Paul was going to have. As a previous board member and chairman of MSL, Paul has been a keen supporter of increased research.

At a recent dinner, former MSRA Chairman Simon McKeon was warmly acknowledged for his six very active years – (he has been on the Board since MSRA's inception) and Paul was welcomed into his new role. Simon is moving on to become Chairman of the CSIRO – another great honour for him.

Working with Jeremy Wright in creating the strategy of MSRA, Paul is eager to see what the future will bring for the organisation. He is proud of the achievements to date. "It is one thing to spend money on research, but you need to

get the results. Scientists working with MSRA have made world class breakthroughs and understandings into this disease. We are getting these results."

Always the financial consultant, it is the business model that is most impressive to Paul. MSRA is effective in getting the right projects in world class



research governance. He is looking forward to it evolving to the next level, to doubling the funds that go into research from all sources. "This will be hard, but it is possible," says Paul.

"MSRA is doing incredible work. The dedication of the people, the groundswell of community support, in particular the focus of MS researchers, is incredible. It is impossible not to be inspired."

Journey to the centre of the brain

The brain is just 2% of our body weight, yet it receives about 20% of the body's blood supply through an extensive network of blood vessels more than 600km long.

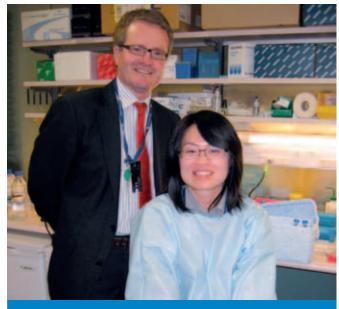
These blood vessels are very selective in what substances they allow to pass between brain and bloodstream. Microvessels in the brain form a **blood-brain barrier** (BBB) that allows essential nutrients (oxygen, glucose, hormones etc) to enter, and waste products to be removed. The integrity of this barrier is vital in maintaining a healthy environment for brain cell function. It also plays a protective role in preventing harmful toxins and viruses from entering the central nervous system; regulating movement of specific drugs, proteins, and blood cells.

The BBB in MS is known to be 'leaky' to immune cells, and new MS lesions tend to form around blood vessels. Prof Simon Hawke from the Brain and Mind Research Institute and the MSRA Brain Bank said that "Inflammation



in and around blood vessels in the MS brain might be responsible for interfering with the body's rigorous security barrier, which protects the brain from potentially toxic agents in the blood."

Along with Dr Ka Ka Ting from the University of Sydney, he is using the latest DNA



PROF SIMON HAWKE AND DR KA KA TING OF THE UNIVERSITY OF SYDNEY ARE INVESTIGATING WHETHER A DISORDERED BLOOD BRAIN BARRIER MIGHT CONTRIBUTE TO DISEASE PROGRESSION IN MS.

technology to work out which genes are turned on or off in brain blood vessels purified from active lesions in postmortem MS tissue. They think that problems with transporter proteins might explain the progressive loss of brain tissue (atrophy) and early symptoms like fatigue or cognitive problems. Only through understanding such changes can bring results leading to effective treatments.

"Using human brain tissue is imperative if we're to understand these disease processes. The MSRA Brain Bank is a growing resource specifically for MS researchers to use and is available because people with MS generously wish to play their part to rid future generations of MS."

To request for your MSRA Brain Bank donor information and consent pack, please call 1300 672 265 or go to www.msbrainbank.org.au



Two new treatments coming to Australia

Current disease-modifying drugs for MS have so far required regular and frequent injections.

Oral therapies represent new treatment options for this chronic disease. Two of these will soon become available: *Movectro* (known previously as Cladribine) and *Gilenya* (known previously as Fingolimod), both for relapsing remitting MS.

Movectro (by Merck Serono) is taken as two short courses annually. These tablets work by destroying specific immune cells called lymphocytes, which play a central role in the development of MS. Gilenya (by Novartis), a tablet taken daily, is also an immunosuppressant. However, it works in a very different way to Movectro. Gilenya stops lymphocytes



from migrating into the brain and spinal cord by locking them in lymph nodes outside the brain and spinal cord.

Movectro has been approved for use in Australia by the Australian Therapeutics Goods Administration (TGA). It is anticipated that the TGA will approve Gilenya early in the new year. Subsequently, Movectro and Gilenya will need to be approved by the Pharmaceutical Benefits Advisory Committee to allow reimbursement and hence affordable access by people with MS. This may take some time.

Prof Bill Carroll, neurologist and MS Research Australia's Scientific Chairman, gave the following comment about these two agents in his editorial in the New England Journal of Medicine. "In the end, individual decisions need to be made based on the risk and benefits discussed between a well-informed patient and his/her clinician, supported by quality safety programs."











F5m Gong Hero

\$4 million dollars in just 5 years... lets make it \$5 million by March

WOW! Thank you all for your events, big and small; F5m has now made it past \$4 million in valuable contributions towards MS research. We celebrate and salute you all - those who cycled, ran, walked, opened their homes, organised balls, dressed up, played music or cheered. You have done something remarkable and have played your part in funding MS research. Here are a few of the events that have helped us get to the \$4mill this year.







MARK BERETTA & JOHN ALEXANDER AT THE TRISH MS FOUNDATION BALL.

In 2010 MS 1000, Mudgee2Sydney walk, the **CharityWorks for MS ball and the Trish MS Research** Foundation ball were events so major and so valuable in our fight for a cure. We like to think you know this already but huge thanks go to Lina Marrocco and her CharityWorks for MS team, Carol and Roy Langsford, Cory Pearce and family, Mike & Katrina Hemingway and Liz Melchoir. These events are significant in every way, the fraternity they display and the incredible amount (a total of \$511,000) raised. The organisation and outcomes leave such an emotional imprint on all of us.

But all events are important – that way we see how things add up. In Brisbane, Canapes & Canvas raised \$16,000 and over five years the dynamic group has topped \$100,000 for F5m. This year's event was held at the Rugby Club at Riverside with 260 ladies enjoying a spring lunch. They deserve the smiles of pride and delight on their faces.



CANAPES & CANVAS COMMITTEE - LEFT TO RIGHT ANNA GOFFAGE, NATALIE WALSH, VICKKI ELLIOTT, EMMA MACFARLANE AND JODIE MADDERS.

Miles for myelin

Some Australian MS researchers and friends in January 2011 will be participating in the community ride of the Tour Down Under. They will ride from Norwood to Strathalbyn, 135km. Chief organiser, Dr Mark Slee, a neurologist at Flinders University, has encouraged other researchers to join him in his fundraising efforts for MS research. 'What started on a whim has really taken shape,' said Dr Slee.

To show support and support Dr Slee or one of the other researchers in their Miles for Myelin quest please visit www.everydayhero.com.au/event/Miles4Myelin



We cannot leave this page without honouring the late Ian Ballard whose idea it was that family and friends of People with MS could raise \$5 million. While we feel he would be pleased about the \$4 million milestone, he would be quick to say... there's still more to be done!

Work Place Giving

Did you know that there is a way to give that makes your donation work harder? - workplace giving. Through workplace giving, your donation goes straight from your pay to the chosen charity - an instant tax deduction. It is hassle free and keeps costs low, so more of your money goes where it is needed most. Ask your employer about workplace giving or call F5m on 1300 356 467. ■

Best and Fairest

The MSRA annual grant round is currently upon us. As you would expect, this is a strict and rigorous peer review process through our Research Management Council (RMC) to determine the allocation of research funding for projects beginning in 2011.

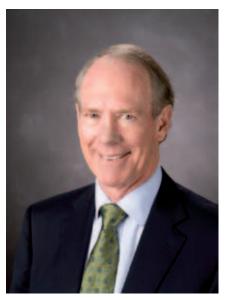
A multi-disciplinary team of scientists, the RMC is an expert group and provides advisory support to the Chairman, Professor Bill Carroll.

It is instructive for everyone interested in research into MS, as with any disease, to understand the process. Full disclosure is important to ensure grants are distributed properly. Any conflict of interest is dealt with and must be avoided. For example, any RMC member associated with a specific application will not review or participate in the discussions or vote on that grant application.

As MSRA Executive Director, Jeremy Wright says "We want to use the contributions wisely and fairly - people support us in good faith and we must respond accordingly. Despite our rigorous procedures we also want to encourage researchers to develop different ideas that will lead to particular

"The generosity of our donors, private and government, hopefully allows us to keep our record of always finding those projects that have sufficient scientific merit," says Jeremy.

The outcome of this year's round will be a new set of projects that will add to an already busy portfolio, being managed by MSRA.



PROF BILL CARROLL - SCIENTIFIC CHAIRMAN MSRA RESEARCH MANAGEMENT COUNCIL



















Blake Dawson





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