

Gene Pooling – you can bank on it

Scientific research can be a game of numbers. The larger the sample size you work with, the more reliable your results.

It's called 'statistical power', and it means that what you have found in your research is more likely to be real and not part of random chance.

That's the impetus behind the recent formation of MSRA's national MS Gene Bank. It brings together the DNA samples from six leading medical research facilities: The Royal Melbourne Hospital, The Howard Florey Institute, Westmead Millennium Institute, Melbourne, Griffith and Newcastle universities.

'All these institutions have already collected a large number of DNA samples from people with MS', says Dr Justin Rubio of the Howard Florey Institute. 'Our institute has access to about 1,000 MS samples and about the same amount for healthy controls.'

The new Gene Bank will function as a 'virtual bank'. The actual samples will remain with the institutions that have collected them but they will be recorded in a central database. A researcher would then be able to search for samples appropriate to their study across the holdings of all the collaborating institutions: around 3,000 samples.

Dr Rubio indicates that a steering committee comprised of key members from the collaborating centres will be established to review applications to the Gene Bank.

After all, DNA samples are a precious and finite resource and research utilising the samples has to be guaranteed to occur according to strict ethical standards.

Once an application has been successful, there are several ways in which samples stored by the Gene Bank could be utilised.

'It may be that samples from the Gene Bank will be tested by a researcher at an independent institution, such as the Australian Genome Research Facility.

Alternatively, a portion of the samples may be transported to the researcher's own lab. Or the research might be conducted in the lab of those who have the samples'.

While there have been some very productive prior collaborations between the Gene Bank members, the establishment of the bank will formalise these relationships and bring the research teams closer together.

'We knew of each other and I have worked with some of the partners but not with others. The bank will also create a focus for other groups to get involved', says Dr Rubio. 'It would be great if other Australian groups with the capacity for patient recruitment, clinical assessment and sample collection could also come on board. The Gene Bank will provide the ideal umbrella to maximise the chance that this will occur!'



► DR JUSTIN RUBIO.

Talking of banking...

Macquarie Bank hosted a lunch with Betty Cuthbert AM as honoured guest.

They also invited Professor Anne-Louise Ponsonby (centre, behind Betty) to talk about the results of the AusImmune Study. Also in the photo are Rhonda Gillam and Simon McKeon, Chairman of MSRA and Executive Chairman of the Melbourne Office of Macquarie Bank.





▶ LACHLAN MATHIESON GIVES JOB JOGGAS THE THUMBS UP.

Job Joggas...

Every month we learn about a person with MS who has not let their misfortune hold them back from coping with everyday life.

This is definitely the case with Debi Mathieson from Mount Tambourine in Qld, who will soon be praised by mothers all over Australia for her creation of a new household companion...the *Job Joggas*.

Based on a magnetic chore reminder system, the product is simple for parents to use and simple for children to understand. It is also available with a variety of different packs for different ages and needs...such as a pre-schooler pack or teen pack, a pet or personal hygiene pack.

The system takes the hassle and stress out of everyday life... making it clear what tasks need to be done, especially by the kids! It has definitely helped Debi since being diagnosed with MS just over 2 years ago.

And a \$1 of every starter kit sold online will be donated to MS research through MSRA – a great Christmas present for everybody.

For more information about Job Joggas, contact Debi Mathieson on 0407 670 900 or email debi@jobjoggas.com.au or visit www.jobjoggas.com.au

Putting your mind into the project

Imagine if your brain could be in the same company as former Prime Minister Gough Whitlam and science guru Dr Karl Kruszelnicki! Well it could be as these two admired men are among the many supporters of a beneficial research program. They have pledged to donate their brains, once they pass away, to the University of Sydney's brain donor program.

Research into the brain is instrumental in any future understanding of the processes that leads to the development of MS – something most readers of this newsletter already know.

With this in mind, MS Research Australia (MSRA) has announced plans to develop a National MS-specific brain and tissue bank as part of the ongoing race to find a cure. MSRA is discussing options with the University of Sydney and the National Neural Tissue Resource Centre based in Melbourne, as well as several other research institutions. It is hoped that these discussions will lead to an integrated program to collect and catalogue the valuable MS brain tissue that researchers badly need.

While a number of brains from MS donors already exist in some institutions their number are still insufficient. If a new program is established, the Australian MS community would be invited to consider brain donation. This opportunity would be available to everyone with MS, whether they die prematurely or from natural causes.

Just as organ donation is the gift of life to someone with organ failure, the donation of a brain tissue could be the key to developing better treatments or even a cure for MS. And just like organ donation, even young people with MS will be encouraged to register as donors.

People who are interested in being a donor should first discuss it with their family as the next of kin also need to give

their consent. Individuals who sign on to the prospective plan will be free to change their mind and withdraw at any time.

Research on brain material that has been affected by specific cognitive conditions is already taking place at the University of Sydney. For instance, one of the programs looks at the effect of stroke and alcohol-related damage to the brain. Another looks at the effects of schizophrenia, highlighting the specific processes which lead to the disease. MSRA similarly hopes that a MS-specific brain bank will be effective in highlighting the causes of the disease.

However, before any pledges can be made by the MS community, MSRA is developing an infrastructure to coordinate with various medical institutions, allowing for the information derived by the brain tissue to be shared by institutions across the country. An ethics committee also needs to be established. It will oversee research projects and ensure correct procedures are followed.

The human brain is thought to be among the most complex structures in the universe, containing more than 100 billion neurons, each linked to as many as 10,000 others. Researchers believe that with adequate resources and enough time, the MS brain and tissue bank will be instrumental to learning more about the disease.



A generous corporate takes on MS – twice!

When Troy McGrath found out that close business partner and co-founder of Foundation 5 Million (F5m), Ian Ballard, had MS, he quickly turned his mind to doing something positive.

His company, AMP financial planners (McGrath Clarke), along with the AMP Foundation, has generously contributed a cash donation of \$10,000 to MS Research Australia through F5m for its Leaving Louis Night in June. This is the second \$10,000 from the AMP Foundation in 2006, with the first coming from Todd Cameron through his Trivia night.

'We have met a few people involved in F5m and their enthusiasm is quite inspiring', says AMP's Troy McGrath. 'When Ian told me he had the disease, I really wanted my company to do something to help researchers find the cause and a cure – and help F5m reach their target of \$5 million.'

Since its founding in 1992, the AMP Foundation has distributed more than \$4 million to the Australian community. MSRA is excited about working closely with the Foundation in the future.



▶ TROY MCGRATH FROM AMP FINANCIAL PLANNERS (MCGRATH CLARKE) SIGNING THE CHEQUE.

Premier event in Adelaide



▶ SINGER CATHERINE LAMBERT WILL PERFORM ON THE NIGHT AND IS ALSO ONE OF THE ORGANISERS OF THE EVENT.

An event for the 2007 calendar... The Gala Dinner for MS Research Australia – April 14, 2007 – to be held at the Ripley Pavilion in the Royal Adelaide Showground.

With guests including the Premier of South Australia, the Hon Mike Rann, and many media personalities, this is set to be one of the biggest nights on the F5m agenda for next year.

Event co-ordinator, Fiona DuRieu, started planning the event in January this year. Having been diagnosed with MS four years ago, she is now in the grip of its debilitating effects and understands more than anyone the urgency for a cure.

Nowadays Fiona is confined to a wheel chair and, on good days, only has the use of one arm. 'With nearly 3 people diagnosed with MS each week in Australia, the race is on to find a cure. It is such a prominent problem,' she says.

Fiona, who was a registered nurse, says it is all the more difficult as she is a single mother raising a teenage son.

The Gala Dinner for MS research is still 4 months out, and with planning well underway there are still many ways for the MS community to show their support and get involved.

Fiona is looking for sponsors of all sizes and forms to help make this night a great success. And naturally a team of volunteer helpers will be welcome!

For more information, or to get involved, please contact Fiona DuRieu (m) 0402 348 679 or email fiona@kostumes4kids.com

▶ JEREMY WRIGHT, ROY LANGSFORD AND THE HON BRENDAN NELSON AT THE DINNER.

Team of the Year

In September this year, a whole host of sporting legends from athletics, rugby, tennis, cricket and golf found themselves on a very different playing field. They were involved with the Trish MS Research Foundation's 'Sports of All Sorts' gala dinner, which raised over \$100,000.

The star of the night was former sprinter Betty Cuthbert AM, who has had MS for the last 30 years and who travelled from Perth to be a part of the celebrations. Sydney broadcaster Alan Jones AM delivered a fitting testimonial, celebrating 50 years since Betty received her gold medals at the Melbourne Olympics.

The Trish Foundation was set up by the parents of Australian cricketer Trish Langsford who died in 2002 after four and a half years in a nursing home with end-stage multiple sclerosis. With the success of the gala ball, the foundation has made more than \$1 million in five years to put toward research into MS. Much of this has been utilised in research that has been jointly funded with MSRA. 'We have a great partnership with MSRA and together we truly believe that we will see an Australian breakthrough in MS research in the near future,' said Carol Langsford, co-founder of the Foundation.



VS for MS

A household name in hair products has put its head down to come up with a new way to help fund research into MS.

Two of VS Sassoon's hair products have gone red this season in an effort to raise awareness and money for research, via MS Research Australia (MSRA) and the MS Society of New Zealand (MSNZ). The new range, called 'Sassoon Red', includes the Ion Shine 2000W Dryer and the Super-Straight Wet to Dry Straightener.

A proportion of the proceeds from every Australian purchase of the scarlet-hued products will be donated to MSRA and in New Zealand donated to MSNZ.

VS Sassoon is aware that the majority of people who are diagnosed with MS are young women between the ages of 20 and 40 – the same demographic of women who are the main users of VS Sassoon products.

The products can be purchased from all major department stores and electric appliance outlets.



MSRA

Multiple Sclerosis Research Australia

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MSRA Partners



Yes, I want to help MS Research Australia

My tax deductible donation is \$ _____

Please debit my: Visa Card Mastercard Amex Diners Club

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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.

To donate now go to www.msra.org.au Donations over \$2 are tax deductible

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Email: _____ Please send me information on how I may support the MSRA in my Will.



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