

Putting the best brains to **MS** research

The recent launch of the national MS Brain Bank, on Tuesday 5th February, by NSW Minister for Science and Medical Research, Verity Firth, exceeded all expectations.

Using the MS Clinic at the Brain & Mind Research Institute, University of Sydney, the launch generated extensive media interest and coverage. And importantly, over 40 calls were received from the public, registering interest in brain donation.

Prof John Pollard AO welcomed everyone including acclaimed scientists, neurologists, MS clinical staff and media. Two special guests, Prof John Prineas and Dr Michael Barnett, are the Australian researchers who have recently pioneered an important new hypothesis on the neuropathology of MS.

Also attending were representatives of the pharmaceutical companies and members of Foundation 5 Million (People with MS who fundraise specifically for MS research, see P3 for their events).

The guests then heard from the Hon. Verity Firth, MS Australia President Graham Tribe, the MS Brain Bank's new Director Simon Hawke and science broadcaster Robyn Williams who told guests that he was happy to offer his 'marinated walnut' anytime!

In launching this new facility The Minister showed genuine enthusiasm, reminding everyone of its co-ordination role with many other institutions. 'In addition, (to our \$500,000 contribution) the NSW Government is sponsoring an award for Medical Research into Multiple Sclerosis as part of this year's Australian Museum Eureka Prizes Award,' Ms Firth said.



MULTIPLE SCLEROSIS BRAIN BANK



▶ NSW MINISTER FOR SCIENCE AND MEDICAL RESEARCH, THE HON VERITY FIRTH, WITH MS BRAIN BANK DIRECTOR SIMON HAWKE AT THE LAUNCH

Being mindful of our resources

The newly appointed Director, Prof Simon Hawke, said the MS Brain Bank has a huge responsibility. 'It receives brain tissue from people with MS who have died. In bequeathing their tissue for scientific research, they are making a final gift to others with the disease. They hope that their gift will lead to a cure for others. So we really see the Australian MS Brain Bank as owned by people with MS and their families. Our brief as custodians of the tissue for donors and their families, is to make certain it will be of most use to scientists working on MS, so that our understanding of the disease increases.'

Prof Hawke's career started in neurology at Royal Prince Alfred Hospital and then on to Oxford and Imperial College London where he studied the impact of viruses in the central nervous system in MS and other neurological disorders. Perhaps most importantly he was among those to set up and run the UK Multiple Sclerosis Tissue Bank, with assistance from the UK MS Society. It was strongly supported by people with MS and their families.

'A brain bank is an important step for those affected by MS now or who may be affected in the future. Optimism in families runs high about finding answers. In the UK when we ran stories in the newsletter about how to register to donate brain tissue, the number of calls went up significantly,' he said.

Prof Hawke said this new Australian facility will play a vital role in a network of brain banks – both nationally and globally – and that new techniques mean our MS Brain Bank aims to be a world leader in collecting and storing high quality tissue. **If you are interested in donating your brain, call MSRA on 1300 356 467.**



▶ GREAT MINDS – (FROM LEFT) GRAHAM TRIBE, JOHN POLLARD, SIMON HAWKE AND JOHN PRINEAS

Diary of an organ donation day

The sequence described here addresses the reality of grieving family members, what they face and the positive outcome. While it relates to organ transplants it is similar to how a brain will be 'donated' for the MS Brain Bank.

9.45am. A hospital calls to let me know a potential organ donor is in intensive care. The person in this case sustained a serious injury and is pronounced dead. I take the details, check the RTA database and Australian Organ Donor Registry. The person was registered as a donor for all organs and tissues. I can proceed. I prepare to meet the donor family as they start grieving.

If the organs can be transplanted we can make a difference to several lives – giving life, health and hope. There are more than 1800 Australians waiting for organs and many will die without a transplant.

11.25am. I arrive at the hospital, talk to the medical and nursing staff and review the medical records. The social worker and I meet the donor family to outline the process and answer any questions. I need to ensure the family is comfortable with their loved one's donation wishes.

Time is important. We have a finite time to retrieve organs before they deteriorate, but the donor family needs time to come to terms with the death.

Most families view organ donation as a positive coming from a tragedy. They seem to take comfort in others getting a second chance at life. It is a personal and intimate time.

1.20pm. Consent is obtained and we can proceed with blood testing. As this is a coroner's case, I confirm that organ and tissue donation won't interfere with their investigation. I speak to the coroner, who gives final approval. During this time I'm in constant contact with tissue banks and staff at the Red Cross laboratories. I organise couriers for blood samples, hospital staff and transplant teams.

3.45pm. I contact the operating theatres to advise of the multi-organ donation and to schedule a time for theatre.

4.12pm. I contact the retrieval teams – in this case liver and pancreas teams – giving them the donor's medical and social history so they can choose suitable recipients. I keep the donor family constantly up to date with progress.

6.55pm. The laboratory results are back and we can proceed. The abdominal transplant team from the transplanting hospital arrives.

11.55pm. Retrieval surgery begins. A liver, two kidneys and a pancreas are removed and ready for transplantation.

3.15am. The donor is washed and dressed and taken to the coroner's morgue. The kidneys are matched with two different transplant recipients and sent by courier. The transplanting team takes the liver with them for transplant into their patient. The pancreas is sent by courier to another hospital. All the transplanting surgeries will take place within hours.

4.30am. Exhausted, but pleased with a successful result, I go home. Four people on the transplant waiting list have been helped through the generosity of the donor and their family.

9am. I advise the donor family that the retrieval is a success. The family member tells me that this has been a positive experience and that he is changing his driver's licence to register as a donor. In a couple of weeks I will notify them of the progress of the transplant recipients.

This article is reproduced with permission from Leigh McKay, the state organ donor co-ordinator for LifeGift NSW/ACT. A longer version first appeared in the Sydney Morning Herald of 3 November, 2007.

\$2 million record for MS research

MS Research Australia (MSRA) will be spending more than \$2 million on MS research in the 12 months from July 2007 to June 2008. This funding will be applied to new programs (as identified both by scientists and MSRA) and used for setting up the MS Brain Bank and MS Gene Bank. All projects are based at Australia's top medical research centres.

'We are proud to now be a major source of MS research funding in Australia' said Jeremy Wright, Executive Director of MSRA – 'and MSRA thanks its many partners and supporters who have made this a new priority.'

The MSRA Board recently approved another \$981,000 of new expenditure to cover projects starting in 2008 – from application grants reviewed recently by the Research Management Council (see the MSRA website: www.msra.org.au for a complete list of recently funded projects). The focus of most of these new grants will be neurobiology with researchers looking at protein regulation and cell behaviour in MS, together with a new look at stem cell development. Two new applied research projects relate to fatigue self-management and muscle control in MS. The grants also cover two fellowships and two postgraduate scholarships to begin early in 2008.

Together with funds applied to ongoing research, including a Queensland study looking at the EBV (glandular fever) link with MS and the Canberra-based MS Longitudinal Study, the total funding from MSRA will amount to a five-fold (500%) increase in support from MS Australia, compared to four years ago (just prior to MSRA being formed).

The other significant funding for MS research in Australia comes from the National Health & Medical Research Council, the Australian Research Council, the National Society of MS (USA) and other private sources. In total, between \$4.5 and \$5 million will be spent this year.

Mountains in May for Mother's Day – May 9-11

What a winning formula for fundraising fun. The picturesque villages of Mt Wilson and Mt Irvine (off the Bells Line of Road, Blue Mountains); superb gardens, historic buildings and a welcoming community. Featuring in the ABC book '1001 Gardens to see before you die' with the WHOLE village listed, not just one garden!

Don't miss out, put this in your diary. F5m supporters Susie Hope and Graham Tribe are organisers of this weekend of festivities. Picnic baskets will be for sale, packed with local produce, enjoy the beautiful gardens (some open to the public for the first time) and historic walks. Oh, and do take Mum! Check www.F5m.org.au or email Susie Hope on louisard@bigpond.net.au or call Neil Robertson 1300 356 467.



▶ WINDYRIDGE' ONE OF THE GLORIOUS GARDENS TO VIEW IN MAY DURING THIS SPECIAL WEEKEND

Adelaide's Gala Dinner – 17 May

Adelaide Showground's Ridley Centre will once again be the venue for the MS Gala Dinner featuring the masterful MC Tim Ferguson and entertainment to include the Fishbowl Barbershop Quartet – straight from their national win as the best in the land.



▶ ADELAIDE'S FIONA DURIEU, NOW A PAUL NEWMAN CHARITY HERO

Organiser Fiona Durieu said the auction items are great. Check the F5m website for more details or call (08) 8360 0800. Proceeds go to MS Society of SA and MS research (the proteomics project at the University of Adelaide under Prof Shaun McColl).

Fiona is a legend in the local fundraising scene and recently was awarded a Paul Newman Charity Hero which gave \$40,000 to MS.

A little help from friends ...

Vale Bernie Banton, AM – having the conditions of asbestosis and mesothelioma did not stop him from being active in the fight for other health-related causes.

'He was a great role model in showing us the way to 'do it for ourselves', said founder of Foundation 5 Million, Ian Ballard. Bernie championed the MS cause



▶ BRENDAN NELSON AND BERNIE BANTON

along with the plight of those affected by industrial diseases. He is pictured here with Brendan Nelson, patron of the MS Trish Foundation, at one of their recent fundraising dinners.

Katrina for Kokoda

One of the everyday heroes to support F5m is keen to have everyone support her walk on the Kokoda Track, mid July.

Katrina Hemingway, who herself is an insulin-dependant diabetic, is doing the walk for her husband Mike, who has MS. 'We like challenges and I'm in training to do this to raise money for research into MS. Her fundraising web page address is www.everydayhero.com.au/Katrina_Hemingway

Other events

Millionaires Golf Day – a scorcher of a day in December saw 65 players and winner Richard Dutton play for fun and contributing towards raising \$20,000.

Throw the book at MS ... register your book group for this night of fun trivia with fiction and fact on June 4 at Paddo RSL or at your own June meeting. Email throw.the.book@hotmail.com for information.

UK Opportunity for MS researchers

Multiple Sclerosis Research Australia (MSRA) and the Macquarie Group Foundation, in conjunction with the UK MS Society, are offering the opportunity for one Australian or UK researcher to undertake postdoctoral training in the UK or Australia respectively.

This 'Macquarie Group Foundation Australian/UK MS Society Research Fellowship' will enhance collaboration by providing flexible opportunities for a researcher to work in a leading laboratory on an important MS project. The award will be from 2009 and will provide funding of up to AU\$110,000 p.a. (or £50,000 p.a.) for three years full-time.

Applications close 30th May 2008. For more information, visit www.msra.org.au

MSRA encourages persons of outstanding ability to make MS research a career. We provide funds annually for fellowships, scholarships and projects that will add to our knowledge of MS. Macquarie Group Foundation continues to support the Australian effort to find the cause, and the cure, for MS.

MSRA

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“Progress in MS Research” conference Melbourne – 15-16 November 2007

Conference notes now on MSRA website



▶ PROFESSOR JIM MCLEOD AT THE CONFERENCE

The 2007 national MS research conference highlighted significant advances in Australian MS research; indicating we are keeping pace with the worldwide effort.

Professor Warwick Anderson, Chief Executive of the NHMRC, opened the conference. The first keynote speakers, Prof John Prineas

from Sydney University and Prof Richard Ransohoff from Cleveland University, presented fascinating insights into the neuropathology of MS and the dynamics of the immune system. This was followed by speakers on a wide range of subjects, with special emphasis on developments in MS genetics (Prof Graeme Stewart, Westmead) and the MS-vitamin D story from Dr Robyn Lucas, ANU.

A summary of new treatments now being trialled came from Dr Helmut Butzkueven (Melbourne University) and a presentation of new technologies, to advance MS research generally was given by Prof Trevor Kilpatrick (Melbourne University). These offered considerable hope that the rate of MS research is substantially quickening. See www.msra.org.au for a full summary.

MSRA Partners

Yes, I want to help MS Research Australia

My tax deductible donation is \$ _____

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I want to support MS Research Australia on an ongoing basis, please charge \$ _____ to my credit card per month until notified.



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Donations over \$2 are tax deductible

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