

Talented, tenacious and titled

... introducing special people in the F5m+ family

Carol and Roy Langsford, OAM

How do you recover from the loss of a daughter to multiple sclerosis? You never do. But Carol and Roy Langsford devote all their waking hours to preventing that tragedy happening to other families.

In the year 2000, Carol and Roy, both recipients of the Order of Australia Medal decided to help find a cure for MS. They started the Trish Multiple Sclerosis Research Foundation. 'Our goals were quite modest but we thought maybe we could help, in some small way,' said the softly spoken Carol. After many of her own events, Carol was introduced to Ian Ballard, the late founder of F5m+. She was a good sounding board for his vision: encouraging all people with MS, their families and friends to raise funds for research – an idea that became Foundation 5 million.

Carol and Roy are passionate about F5m+ and regularly attend the monthly meetings. 'We laugh and we cry but mostly we work hard for a common goal – it has brought together a great bunch of people. This is such a tribute to Ian,' Carol said. The F5m+ network is involved in different events but the mutual support is genuine.

Carol and Roy are often overwhelmed by generosity. 'In 12 years, raising around \$2.5m is remarkable. In some ways, though, more rewarding has been meeting amazing and



ROY AND CAROL LANGSFORD DOING THEIR BEST TO KISS GOODBYE TO MS.

dedicated scientists, and the friends we've made!

A scientific research committee, which receives input from MSRA's Research Management Council, guides the Foundation's choices for research projects. Their investment has offered a good 'return' for MS research. More information is available at www.trishmsresearch.org.au as well as details for this year's major fundraiser, with a *Kiss Goodbye to MS* theme, on 15 September at the Hilton Sydney Hotel. ■

Lina Marrocco, OAM

An equally remarkable person in the F5m+ network is Lina Marrocco; whose energy is infectious. How did she get to be one of the great F5m+ supporters?

'You can blame [or praise!] my neurologist Dr Helmet Butzkueven for that. After my diagnosis in 2002 he learnt that I was involved in fundraising so he said, perhaps in jest: maybe raise funds for MS research?' she said.

Only later did Lina realise that Dr Butzkueven is also a recognised scientist at the Florey Neuroscience Institutes and the University of Melbourne.

STANDING OUT IN CRIMSON, LINA MARROCCO.

So Lina jumped at the challenge and used her expertise to hold the first major ball for MS research in 2004. Her scientist husband is yet to benefit from her fundraising; but she cheekily suggests he might change fields to MS Research!

This year's 'Stand out in criMSon' Ball (on 20 October at Docklands in Melbourne) will be another great event for Charityworks for MS. Her long standing team of nine (three with MS and six friends and a family of people with the disease) are 'brilliant and their capacity for work knows no bounds'. A talented group of decorators is working on plans to make a splash – the venue will have a graffiti theme. The 2012 ball will bring Lina's total to over \$750,000 from just five events. Visit www.charityworksforms.org.au

Lina says Ian Ballard's voice still rings true for her. 'Ian taught me to think big, break it down and make it happen. I aim for the sky, but I'm happy to reach the treetops!' This is the spirit that has spread into the wonderful group of people who form F5m+, everything you do is an important contribution to our goal; to prevent, cure or better treat MS. ■



The Amazing People Project

Amazing people needed for The Amazing People Project. This campaign aims to inspire everyday people to do something amazing – for themselves and for five charities.



Be Amazing, the goal is for 250 people to raise \$250,000 in 250 days (\$1,000 each). People select a variety of ways to get involved (run a race, hold a garage sale, abstain from a bad habit) and whatever they raise gets distributed evenly amongst five very worthwhile charities – including F5m+ and MSRA.

To join the Amazing People Project visit:

www.theamazingpeopleproject.com ■



MSRA Partners



Yes, I want to help MS Research Australia

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

- My one off tax deductible donation is \$ _____
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Please charge \$ _____ to my credit card per month until notified.
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- OR I have enclosed my: Cheque/Money Order payable to MS Research Australia.

- Please note here if your donation is made in memory of someone or for a function.
name of person / function name:

- Please send me information on how I may support MSRA in my Will.
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Evaluating treatment decisions in MS

Earlier this year Dr Tomas Kalincik was awarded an MSRA Fellowship to undertake research at the University of Melbourne to evaluate clinical treatment decisions in MS.

Described by his PhD supervisor as 'that rare mix of basic scientist and clinician' Dr Kalincik is ideally suited to this project and is a great asset to Australian MS research.

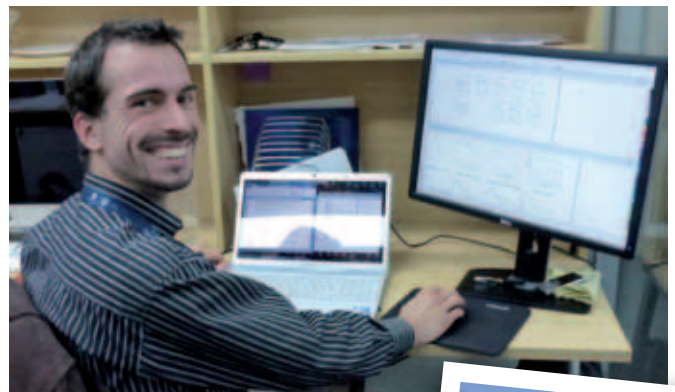
In his home city of Prague, Dr Kalincik worked in a busy clinic that cares for over 4500 people with MS. While honing his clinical experience, he has also worked extensively on research projects and developed an outstanding aptitude for statistical analysis.

'This dual role allows me to take questions of individual patients to large populations in search of the evidence and then bring the answers back to patients', said Dr Kalincik. 'It is good when a patient asks about her or his prognosis, to be able to start the sentence with 'We have actually looked into this...'

In the current research Dr Kalincik will work with internationally respected MS researcher, A/Prof Helmut Butzkueven at the University of Melbourne. They will take a statistical look at the outcomes of different treatment decisions. A variety of therapies are available to reduce the relapses of MS, however responses vary greatly. There is also a gap in our knowledge regarding the potential outcomes for those who need to switch between treatments.

Currently in Australia, the immune-modifying medications, interferon beta or glatiramer acetate, are considered 'first-line' treatments, chosen as the initial therapies for most people with relapsing remitting MS. Switching from one drug to the other often occurs if the response to the first choice is unsatisfactory. Escalation of treatment, by switching to one of the 'second-line' drugs such as natalizumab or fingolimod, is another option but carries a risk of potentially more serious side-effects and higher costs. To date there is no evidence on the long-term outcomes of switching between the first-line drugs or escalation to second-line treatments.

The project will use data from the powerful MSBase database and aims to develop an on-line 'risk calculator' to guide treatment decisions for neurologists and their patients. The MSBase registry is the largest international MS registry. It contains clinical data from over 20,000 patients, including many from Australia. Dr Kalincik will use this data to address



DR TOMAS KALINCIK.



these questions of long-term outcomes of treatment decisions in groups of patients with different sets of characteristics.

'This will be like a 'pseudo-randomised-controlled trial' using clinical data from existing patients. MSBase allows us to construct retrospective or virtual trials, using data collected in routine clinical practice. The strengths of this approach are its cost-effectiveness, its broad sample of patients in real clinical settings and the statistical power of a large number of patients with long-term follow-up,' said Dr Kalincik.

While Dr Kalincik loves the outdoors and photography, and is a talented musician and linguist, clearly this work is his greatest passion. 'I like the process of searching for answers to questions which matter to patients. It is inspiring for me, to see the enthusiasm with which the people with MS, their families and communities all engage in the issues. I wish to thank them for their support; this way we get to face MS not as sole fighters but as a team,' he said.

MSRA looks forward to the results of this research which we hope will help lead to fewer relapses and reduced disability progression for people with MS. ■

Forging state connections

A collaborative forum was held in July to connect leading MS researchers and clinicians from around New South Wales. The NSW MS Research Network brings researchers together to discuss new proposals and foster MS research collaborations in NSW.

Meeting at the Macquarie Graduate School of Management, the researchers showcased their work, developed ideas and formed and strengthened professional ties. Researchers discussed their upcoming research projects to determine how partnerships might be useful in attracting more funding to MS research in NSW.

Prof Graeme Stewart, the NSW Network Chair and leading immunology researcher, spoke about the way genetics plays a role in whether people with MS respond to treatments. Prof Stewart and A/Prof David Booth, a geneticist at the Westmead Millennium Institute, would like to organise a working group regarding an MS-specific Biospecimen Registry. This registry would hold different samples from people with MS such as DNA, serum, immune cells and cerebrospinal fluid to assist many MS research projects.

Dr Jeannette Lechner-Scott, a neurologist based at the John Hunter Hospital in Newcastle, has a particular interest in cognitive aspects of MS and the role of MRI in treatment decisions. She was keen to see a more uniform clinical screen of MS across NSW and is interested in a clinical information database to help with tracking the progress of people with MS. Ms Wendy Longley, a Senior Clinical Neuropsychologist for MS Australia and MS researcher, has a common interest in standardising cognitive screening in MS. She also presented



MEMBERS OF THE NSW MS RESEARCH NETWORK.

her clinical trial looking at the benefits of neuropsychological assessment in people with MS.

Dr John Parratt, a neurologist from Royal North Shore Hospital, spoke about his research into the neuropathology of MS. One of his research areas focuses on the identification of autoantibodies in MS. Dr David Brown, of St Vincent's Centre for Applied Medical Research, presented his work on the dendritic cells of the immune system and brain and the role of the cervical lymph nodes in MS. Dr Brown is looking into the potential of therapies delivered directly to lymph nodes and has some promising results in laboratory models. Both Dr Parratt and Dr Brown were interested in expanding their current findings in collaborations with other members of the network.

The NSW MS Research Network provides a stimulating environment for researchers across the spectrum of MS research from neurology, to basic research and allied health. This mixture lends itself to the forging of collaborations based on complementary expertise and common research themes. Working teams have now been established to further investigate the potential for the Biospecimen Collaborative and Clinical Capture database with a follow-up workshop planned for the coming weeks.

'We were very pleased with the outcomes of the meeting,' said Prof Graeme Stewart, 'and we are excited about the upcoming projects and collaborations identified!'

Professor William Carroll receives Western Australian of the Year Award

Early last month, Prof William Carroll was named Western Australian of the Year in the business and professions award category, recognising his noteworthy contributions to medicine, in particular research for multiple sclerosis (MS).

Prof Carroll, one of Australia's most prominent neurologists, has dedicated more than 15 years to raising the profile of MS research in Australia as an expert and advocate for people with MS.

Prof Carroll is the chairman of the MSRA scientific committee, a member of the boards of MSRA, Multiple Sclerosis Australia and the MS Society of WA.

In the capacity as Chair of the Research Review Board Prof Carroll helped to establish MSRA's research strategy, and as Chair of the Research Management Council, continues to oversee the annual grant application and review procedure.

Last year Prof Carroll was also awarded the prestigious John Studdy Award in recognition of his outstanding, consistent and selfless provision of meritorious service to people living with MS. ■



PROF WILLIAM CARROLL.
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Bequest for a cure

MSRA will this month work with over 130 Australian charities to help raise awareness of the importance of gifts included in wills.

It's a common myth that you have to be wealthy to leave a gift in your will, but nothing could be further from the truth. After taking care of family and friends, you'll be amazed at what one final gift, no matter how big or small, can do.

Whatever the amount, we're extremely grateful for any gift that has been included in a will for us, as it helps us to

continue to fund Australia's promising MS research and the researchers working hard to find the cause and cure of MS.

For instance last year gifts in wills enabled MSRA to fund four different Incubator Grants. These are small grants that seed the earliest stages of innovative and promising new research efforts. More often than not MSRA-funded incubator grant recipients go on to receive major project funding from either MSRA or the National Health and Medical Research Council.

On the 17-23 September, MSRA and "Include A Charity" will be generating media activity to help people understand the value of a bequest to benefit society through a charity as well as remembering their loved ones.

Your bequest to MSRA will help with the search for a cure. For further information you can ask any professional will-provider or solicitor, visit www.msra.org.au/bequests or visit www.includeacharity.com.au ■

include msra

Help the work live on.



IN-DEEP offers depth of data on MS

A soon to be launched website will summarise the highest quality science about MS research and treatment options. The format aims to enable people with MS and their families to relate information to their own individual circumstances.

The MSRA-funded IN-DEEP project is led by Dr Sophie Hill at La Trobe University in partnership with MS Australia and people with MS.

The website is the culmination of nearly two years investigation by the La Trobe team into online health information-seeking by Australians with MS. The team has drawn on international best practice for explaining medical research in plain language and has conducted user testing with Australians with MS and their family members. Look

out for details of the website in the coming weeks. For more information about the research project visit: www.msra.org.au/in-deep ■



New Co-Director for MSRA Brain Bank

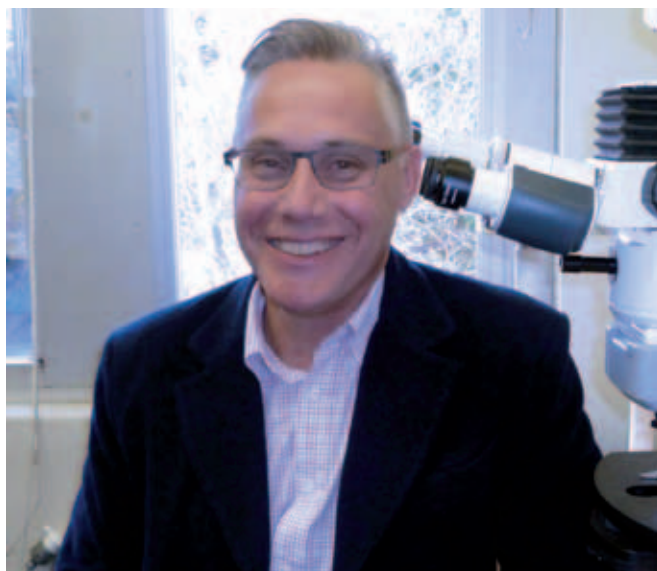


MSRA is pleased to announce Dr Michael Buckland as the new Co-Director of the MSRA Brain Bank working alongside Dr Michael Barnett.

Dr Buckland is head of Neuropathology at Royal Prince Alfred Hospital in Sydney and an Honorary Associate at the University of Sydney. He received his medical degree from the University of Sydney in 1993, and his PhD in Neurobiology from the University of New South Wales in 2000. He became Fellow of the Royal College of Pathologists in 2004, and has since devoted his pathology expertise to matters of the brain. Dr Buckland adds considerable experience in the diagnosis and characterisation of brain tissue and we are pleased to welcome him to the team.

'Collaboration among clinicians and pathologists will be integral to understanding MS,' said Dr Buckland. 'I am proud to be able to provide the pathological expertise that will facilitate MS research in Australia. This will be a world class bio-repository.'

Dr Buckland joins the MSRA Brain Bank just as operations move to a new location at the Brain & Mind Research Institute (BMRI) at the University of Sydney. This state of the art facility will provide MS affected brain tissue to researchers around Australia.



DR MICHAEL BUCKLAND.

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

Clinical trials – symptom management

For many people, the term 'clinical trial' brings to mind large trials for new drugs. However, clinical trials regarding symptom management are also essential to bring patients effective, evidence-based care that allows them to live well with their MS.

Researchers and allied health practitioners around Australia are involved in a wide range of clinical research and trial activities to improve the management of MS symptoms. For people with MS, taking part in clinical trials can provide them with access to the most up-to-date treatments. An added benefit is increased care and surveillance of symptoms that comes as part of the trial procedures.

For instance, urinary incontinence is one of the most common symptoms in MS and there are ways to treat and manage this issue. (Visit the MS Australia website: www.msaustralia.org.au for further information). It can, however, be a difficult area for patients to discuss. A new trial run by nurses in Melbourne aims to improve screening for this problem and provide more targeted and effective treatment

and management strategies. The benefits should be seen in improved symptoms and quality of life for people with MS.

In Adelaide, Dr Chris Barr, a Clinical Rehabilitation specialist at Flinders University, has been investigating treatments for foot drop, walking fatigue and falls in MS. Electrical stimulation devices and orthotic devices have been tested and results can be expected soon. Dr Barr is also now running a new trial investigating the use of cooling vests during exercise in people with MS. He aims to test whether keeping core body temperature lower, during exercise, can reduce the effects of fatigue on balance and walking ability.

For further information on these and other clinical trials, visit www.mstrials.org.au

