

New MS Brain Bank gives hope for a cure

THE MS BRAIN BANK WAS RECENTLY LAUNCHED AT THE MS CLINIC AT THE BRAIN & MIND RESEARCH INSTITUTE IN SYDNEY BY NSW MINISTER FOR SCIENCE AND MEDICAL RESEARCH, THE HON VERITY FIRTH MP AND WILL TAKE MS RESEARCH TO A NEW LEVEL.

THIS exciting new facility is dedicated to the collection of brain tissue for researchers to find out more about MS. Already many calls have been received from the public, registering an interest in brain donation.

The new Director of the Brain Bank, Professor Simon Hawke said, "We really see the Australian MS Brain Bank as being owned by people with MS and their families."

"So far research has relied on animal models with limited success as it does not accurately reflect some aspects of MS in people. Now, this MS Brain Bank will provide the valuable human tissue for scientists around Australia doing advanced MS



NSW Minister for Science and Medical Research, the Hon Verity Firth MP and Professor Simon Hawke at the launch of the Brain Bank.

research," said Prof Hawke.

"This facility should give our researchers an edge," said Jeremy Wright, Executive Director of MS Research Australia.

If you are interested in donating your brain, call MS Research Australia on 1300 356 467.

Neighbours help us raise awareness and build support

AN MS STORYLINE FEATURED ON POPULAR TELEVISION DRAMA, NEIGHBOURS, IS ALREADY INCREASING COMMUNITY AWARENESS AND UNDERSTANDING OF MS IN LEAPS AND BOUNDS. FOR THE FIRST TIME IN AUSTRALIA, WE ARE ABLE TO COMMUNICATE TO A MASS AUDIENCE ON THE LIFELONG MS JOURNEY IN A WAY THEY CAN CONNECT WITH.

OFTEN considered a hidden disease, MS presents symptoms that are often not visible. This can make it difficult for the general public to recognise what it is like to live with MS, not only for the individual but those close to them – their family and friends.

Susan Kinski, the Neighbours character living with MS, brings these symptoms and the reality of living with the disease into people's living rooms. Those watching the show have seen Susan experience difficulty with her vision, slurred speech, extreme fatigue, numbness and partial paralysis and how this has affected



Actress Jackie Woodburne, who plays Susan Kinski, a character on Neighbours living with MS.

relationships within her family and social circle. Given Susan is a permanent character on the show; she will continue living with the disease and further educate the public on it being a lifelong disease.

Before developing the story, the Neighbours team were committed to learning more about MS – meeting with our Medical Director and an MS Ambassador to ensure their planned portrayal of Susan's diagnosis and MS progression was correct. In fact, when the story aired our MS Ambassador commented it was like looking back on herself 20 years ago.

Neighbours has been seen in 57 countries to date to a daily audience of 120 million. It is currently on air in Australia, New Zealand, the UK, Ireland, Africa, Iceland, Dubai, Cyprus and Belgium, providing a huge audience for the MS message.

Neighbours can be seen from Monday – Friday on Ten and affiliate networks at 6.30pm.

MS EVENTS

The MS Walk & Fun Run on Sunday June 1 will kick off MS Awareness Week in Sydney and Melbourne. It's a great way to join friends, family, workmates or your sporting team to make a difference to people living with Multiple Sclerosis. Last year we raised a record \$360,000 and this year we've set our sights on \$450,000.

In Sydney choose from the fully accessible 9 km, 16 km or the new 5 1/2 km option for those who prefer a shorter stroll. All options are stroller friendly and include spectacular harbour views and some of Sydney's finest parks and gardens. All walk courses start and finish in Hyde Park.

Runners have a challenging and spectacular 8km course from Bradfield



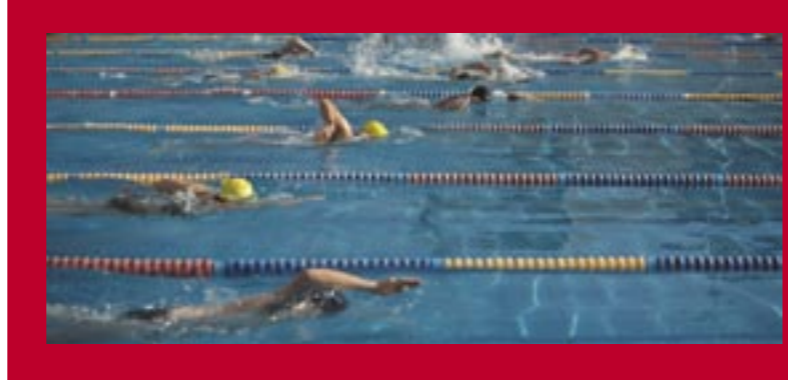
GET INTO MS AWARENESS WEEK AND STROLL, SPRINT, SKIP, RUN, WALK OR ROLL – BUT WHATEVER YOU DO, MAKE SURE YOU'RE PART OF THIS YEAR'S MS WALK & FUN RUN.

Park to Balls Head Reserve and back finishing in front of Luna Park.

Melbournians have a choice of fully accessible 5km or 10km walks and a 9km fun run around picturesque Albert Park Lake, starting and finishing at beautiful Palm Lawns.

Entertainment, food and lots of fun is guaranteed in both cities.

Get moving for MS and take the first step to be part of this event by **registering online at www.mswalk.org.au or phone Melbourne (03) 9845 2718 or Sydney (02) 9413 4166.**



MEGA SWIM – SYDNEY

Following the fantastic success of Mega Swim in Melbourne over the last few years we're now bringing this 24 hour swimming event to Sydney. We're planning on making a big splash at the **Sydney Olympic Pool, Homebush on Saturday 14 and Sunday 15 June. Check out www.mssociety.org.au/megaswim or call (02) 9413 4166 for details.**

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MS KEYNEWS AUSTRALIA AUTUMN 2008

SPECIAL MS AWARENESS WEEK ISSUE



LAUNCH OF GROUNDBREAKING NEW RESEARCH

LINA MARROCCO: TOP FUNDRAISER WINS AUSTRALIA DAY AWARD

NEIGHBOURS HELP US RAISE AWARENESS AND BUILD SUPPORT



■ FROM THE CEO'S DESK

Get Involved in MS Awareness Week

WELCOME to this special MS Awareness Week issue of Key News.

As we approach MS Awareness Week, I can report to you that the MS Society of NSW/Vic is making significant achievements for people living with Multiple Sclerosis.

One of the most groundbreaking achievements is our new research and treatment model into how a healthy mind and body can work together to help people manage and control their MS. Our new way of thinking impacts on the management of many other diseases. I urge you to read our main story for more information on this exciting new approach.

In addition, the MS Brain Bank was recently launched by the NSW Minister for Science and Medical Research, Verity Firth. This new facility will enable Australian researchers to collect brain tissue to find out more about MS and give hope for a cure to people with MS around the world.

Both of these initiatives are placing Australia at the forefront of groundbreaking research into the cause, cure and possible prevention of MS. We are proud to be involved but also want to recognise your contribution. Without your ongoing support we would not be able to offer these long-term research programs that allow us to be one step closer to a life free from MS.

Whilst we have many achievements to be proud of during MS Awareness Week, we cannot forget there are still five Australians told each working day that they have MS. We are making great progress but there is still a long way to go.

This year's MS Awareness Week will take place from June 1 – 7, and aims to raise awareness of MS in the community. MS Awareness Week is crucial in building wider understanding and support for people with MS so keep an eye out for our public awareness campaign, media coverage and events.

See our back page for how you can sign-up to take part in the MS Walk and Fun Run in Sydney and Melbourne, kicking off the week on June 1. If you aren't able to participate this year, why not support someone through the MS Readathon? For more information, visit the website: www.msreadathon.org.au

I hope you enjoy this issue of Key News. Thank you again for supporting us – you are making a difference to the lives of people with MS.

Bill Younger
CEO, MS Society of NSW/VIC

To provide feedback, make a donation or for more information please call 1800 CURE MS or visit www.mssociety.org.au

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■ MS LIFE



Lina with her husband Sab Ventura and her two children Mergy and Millie

Top Fundraiser Wins Australia Day Award

INSPIRATIONAL VICTORIAN LINA MARROCCO WAS RECENTLY AWARDED AN ORDER OF AUSTRALIA MEDAL ON AUSTRALIA DAY IN HONOUR OF HER COMMITMENT TO RAISING FUNDS FOR MS RESEARCH.

LINA has been living with MS for 11 years. She says “living with MS is terribly frustrating and unpredictable. It is certainly an emotional rollercoaster. But I will not let it define me. Things happen for a reason – and I am committed to making a difference with this disease.”

As well as raising two young children, her and the Charityworks for MS Committee have raised more than \$270,000 in the past three years. Her difficult days and commitment to fundraising would not be possible without the unwavering support of her husband, Sab Ventura and her children, Mergy (11) and Millie (8).

To give more support to people like Lina and Sarah, and to keep researching to find a cure, we need to build awareness of MS in the community through campaigns and events such as MS Awareness Week.

“My team and I fundraise because we are committed to helping the scientists to find a cure. I am the smallest piece in a very large jigsaw puzzle, but the puzzle will not be complete without every single piece,” Lina said.

“Science is painstakingly slow and exceedingly expensive. \$100,000 doesn't really go that far – but every cent counts. That's why it's important for us to keep raising money.”

Lina recently completed a walk on role in Neighbours – stay tuned over the next few months to see if you can spot her.



Sarah Ross-Smith is one of the thousands of young women in Australia living with MS.

One of the many young women living with MS

EACH AND EVERY WORKING DAY FIVE AUSTRALIANS ARE TOLD THEY HAVE MULTIPLE SCLEROSIS. 75% OF THESE PEOPLE WILL BE YOUNG WOMEN AND THEIR AVERAGE AGE AT DIAGNOSIS IS 30. THEY ARE AT THE PRIME OF THEIR LIVES; THEY ARE WORKING, PERHAPS ENGAGED OR MARRIED AND MAY HAVE YOUNG CHILDREN OR PREPARING TO START A FAMILY OF THEIR OWN.

MEET Sarah Ross-Smith. Sarah was an up and coming 34 year old lawyer with a 2 year old son, Xavier, when she started experiencing terrible headaches and problems with her eyesight. She was later diagnosed with Multiple Sclerosis.

After living with MS now for four years, Sarah says the part of MS that affects her most is the unpredictability. “The worst thing is going to bed and praying that I wake up feeling ok. If

I wake up with a bad leg or blurry eyes, it affects our whole family,” Sarah says.

Sarah has used her MS to help other people living with the illness, by lobbying Governments to support people with MS and fundraising for research into finding a cure. Recently, Sarah was one of the leaders in the campaign to get a breakthrough MS drug recommended for listing on the PBS.

“When I heard the news the drug had been recommended for the PBS I was in a shopping centre and I literally sat down and cried. I knew that this could mean a great deal of relief for many people living with MS and that, for those 5 people diagnosed with MS every day, their doctors could finally say “there is hope,” she said.

■ MAIN STORY

UNDERSTANDING HOW THE MIND AND BODY WORK TOGETHER



THE MS Society of NSW/Vic is pioneering an exciting and groundbreaking new research and treatment model – Psychoneuroimmunology (PNI) in MS.

This new model is based on theories of how the mind and body can work together to help people manage their health and reduce their chances of developing disease.

PNI is about supporting people with Multiple Sclerosis to keep their immune systems healthy - exercising regularly, eating healthy food, getting enough safe sun exposure, managing mood and stress and avoiding negative thoughts.

The PNI model is teaching us more about what we can do to improve our

health and therefore how we can keep MS better controlled.

“PNI encourages people to take an active role in the maintenance of their health and management of their illness,” Dr Gary Fulcher, Senior Clinical Psychologist and Research Development Officer at the MS Society said.

“It helps people with MS understand the role of stress in their condition and the best ways to manage it.

“We hope that more research into PNI

“PNI will lead us to crucial new discoveries.”

will lead us to crucial new discoveries about the cause of MS and how to minimise the risk of getting MS. We haven't been able to make these discoveries in over 100 years of conventional approaches and we believe that using this extra dimension to research could make the difference.”

The MS Society will be encouraging more research in this area around the world to get closer to making these crucial new discoveries. To do this, we will be establishing a PNI website to enable researchers and health professionals to debate and discuss PNI online.

“This is a revolution in thinking about MS, as well as many other illnesses,” Dr Fulcher said.