

Getting results for people with MS

BY WORKING WITH STATE AND FEDERAL GOVERNMENTS, MS AUSTRALIA – ACT/NSW/VIC HAS RECENTLY ACHIEVED WINS FOR PEOPLE WITH MS AND THEIR FAMILIES.

THOUSANDS of people living with MS across Australia were given new hope for the management of their illness, following the listing of the drug Tysabri on the Pharmaceutical Benefits Scheme (PBS) on 1 July.

Dr Bill Carroll, Chairman of MS Australia's Research Committees said this will be a welcome addition to the range of treatment options for patients

"MS Australia would like to acknowledge the Federal Government for making such a large economic commitment and recognising the hope this treatment brings to many people with MS," said Dr Carroll.

In another win for people with MS, the Victorian State Government announced \$2.5 million in their May Budget to increase the Medical Cooling Concession after an intensive campaign run

More concessions for MS

VICTORIAN multiple sclerosis sufferers have won their battle for an expanded summer electricity bill concession. Previously only been available for the summer months, the State Government has now extended the concession to apply for six months of the year.

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by MS Australia – ACT/NSW/VIC.

The Medical Cooling Concession provides a discount to people with MS on low incomes for their summer electricity bill. This is crucial because around 80% of people with MS experience *anhidrosis* (heat intolerance). This means that as little as ¼ of a degree increase in core body temperature can trigger a significant increase in MS symptoms such as extreme fatigue and pain.

This was a major win for our Advocacy team, who worked tirelessly with the Victorian Council of Social Services, other community groups and people with MS, who wrote to their local politicians and the media. This shows what can be achieved when we can all work collaboratively for the good of people with MS.

World photography exhibition for MS in Sydney

SUNDAY 1 JUNE 2008 MARKED THE AUSTRALIAN LAUNCH OF THE INTERNATIONAL IMAGES OF MS PHOTOGRAPHIC EXHIBITION AT THE MS WALK & FUN RUN IN HYDE PARK, SYDNEY.

THE exhibit featured 38 black and white photos of people from around the world who are living with MS. The exhibition was unveiled in Rome and is now travelling the world to dispel myths about MS and show what people with MS can achieve with the right support, personalised services and a positive outlook

The exhibition included photographs of two inspirational Sydney women with MS



Tana Bullen, who appeared in 'The Images of MS' exhibition

– Sarah Ross-Smith, a successful lawyer and mother of one, and Tana Bullen, a new mother and personal trainer.

Tana and Sarah have shown that the disease may be debilitating but has in no way stopped their positive outlook on life. Both women are working, caring for children and living life to the full.

"I feel like I'm doing more now than prior to the diagnosis. I'm happier, fitter, and more fulfilled with my life," said Tana.

"Having MS doesn't necessarily need to stop you from doing the things you want to do. It's important to have a positive attitude and focus on what you can do," she said.

"MS has taught me to re-evaluate what's important in my life. It has shown me that life is about making a difference and it's about always having hope," Sarah reflects.

The exhibit was viewed by over 3,000 participants at the MS Walk and Fun Run, which also began in Hyde Park on 1 June. *The story received news coverage in the Sunday Telegraph, the Sydney Morning Herald, the Manly Daily, and various daily radio programs across Sydney and regional NSW.*

The Armed Man

ON 22 November 2008 Heather Scott will be hosting a concert as a tribute to her late husband who ended his battle with MS in 1983 after living with it for 25 years. The concert will be a performance of a piece of music called The Armed Man: A Mass for Peace, written in 2000 for choir and orchestra by Welsh composer Karl Jenkins. *The Armed Man will take place at 7.30pm at St Stephen's Uniting Church, Macquarie St, Sydney. There will be refreshments with the performers after the concert. For more details please contact Heather on (02) 9489 9411.*

MS EVENTS

Sydney to the Gong Bike Ride aims to raise \$1.7 million

In true Gong style, the original course starts at St Peters where riders will pedal 90km to Wollongong via the Royal National Park and experience the spectacular Seacliff Bridge from the saddle alongside 10,000 other cyclists.

If you don't think you have the pedal power to go the full distance, start at Heathcote and follow the short and scenic 56km course which captures all the highlights of the original route.

Raise more than just a sweat on the Gong Ride and help us fundraise \$1,700,000 to support people with MS.



WE INVITE YOU TO GET ON YOUR BIKE ON SUNDAY, 2 NOVEMBER AND BE PART OF AUSTRALIA'S PREMIER ONE DAY CYCLING EVENT – THE MS SYDNEY TO THE GONG BIKE RIDE.

For the most rewarding experience on two wheels, register and fundraise online at www.gongride.org.au.

Don't have the puff to participate but still want to be part of the action? We are currently seeking enthusiastic volunteers to join our team and fill over 400 positions

on the day. These positions include route marshals, information and check-in, transport assistants, equipment and signage crew members and bicycle mechanics. You're never too old or young to help out on the Gong Ride. Complete an application form online at www.gongride.org.au or call (02) 9468 8366.

MS Walk and Fun Run – Breaking More Records

THE ANNUAL MELBOURNE AND SYDNEY MS WALK AND RUN WAS YET ANOTHER RAVING SUCCESS ON SUNDAY 1 JUNE WITH \$450,000 RAISED FOR PEOPLE WITH MS.



OVER 2,500 Sydneysiders put their best foot forward and got moving for MS around Hyde Park and 1,500 participants in Melbourne showed their support by walking or running around Albert Park.

A huge thank you to everyone who collected sponsorship, made a donation or ran a special event. Special mention needs to go to Perry Lopez, team captain of Team Gopez who took 1st place on our podium for the Highest Walk Fundraising Team, raising more than \$60,000 for people with MS. We would also like to extend a huge thanks to our 300 volunteers, sponsors and community groups who assisted in making both events such a success. We hope to see you in 2009 as we go bigger and better!

3 Amigos to cook up a storm at Taste Orange dinner

THE SEVENTH ANNUAL TASTE ORANGE FOR MS DINNER ON 23 SEPTEMBER WILL BRING THREE OUTSTANDING YOUNG CHEFS TO SYDNEY TO SHOW WHAT THEY CAN DO WITH ORANGE'S FINEST FOOD AND WINE.

THE Taste Orange for MS dinner began to showcase the diverse produce and wine of the Orange region and is now one of Sydney's most strongly supported charity gourmet events. This dinner will be held at Eastern Suburbs Leagues Club and will the launch of Orange and Waverly Council's Taste Orange Week in Bondi from 23-28 September. Sydneysiders will have the opportunity to experience first hand the new innovative, creative, sophisticated signature dishes of three highly acclaimed chefs from the Orange region – Tony Worland, Shaun Arantz and Scott Want. *For tickets call (02) 9468 8300 or email mmorgan@mssociety.com.au*

Support people with MS on the Spring Cycle

MS Australia – ACT/NSW/VIC is excited to announce that we will be the charity partner for the 2nd year running for the City of Sydney Spring Cycle on Sunday 19 October. The cycling community has shown tremendous support for the MS Society in the past and we are hoping to raise \$100,000 from this event. If you have a fundraising itch and just cannot wait for the Gong Ride in November, get involved in the Spring Cycle. It's great training for the Gong Ride and better still, another opportunity to show your support for people with MS. *For further information, email events@mssociety.com.au or call (02) 9468 8345.*



HISTORIC MOVE: MS SOCIETIES MERGE

MS WALK AND FUN RUN: BREAKING MORE RECORDS

MS CONNECT: HELPING PEOPLE WITH MS



■ FROM THE CEO'S DESK

Enhancing our services for people with MS

WELCOME to the winter issue of Key News.

Much has happened since our last issue and with your help we have continued to make impressive progress in supporting people living with MS.

Very recently, we were proud to welcome the MS Society of the ACT. The merge is yet another historic move towards the integration of the MS Societies in Australia and a commitment from our organisation to enhance programs and services for people living with MS in South East NSW and the ACT. Further details on the merge are outlined within the article "MS Societies Merge" on page two.

We continue to pride ourselves on working collaboratively with Governments and other community organisations for the benefit of people with MS. In this issue you'll also read about two significant wins for people with MS that we have been able to achieve.

I am also pleased to report that MS Awareness Week was a success. Thank you to all those people who participated in the MS Walk and Run, supported a child through the MS Readathon or gave generously to our tax appeal.

The funds we raise through these initiatives are essential in allowing us to help people with MS. I encourage you to read the article on page three about the significance that our physiotherapy classes have had on Sarah-Jane's life. Since participating in these classes she comments on how strong she feels. So, each time you walk, run, read, donate or sponsor just know that you are not only making a difference to Sarah-Jane, but many more people living with MS.

As a disease affecting more young Australians each day, your support is crucial and very much appreciated. Please remember it's never too late to give and is as easy as calling 1800 287 367 or logging onto our website: www.msaustralia.org.au.

I hope you enjoy reading this issue of Key News and find it both informative and inspirational.

Bill Younger
CEO, MS Australia – ACT/NSW/VIC

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

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■ MS LIFE



Community Support Worker Christine Comito answering calls in MS Connect

MS Connect: Helping people with MS

MS CONNECT IN THE ACT AND NSW, AND INFOLINE IN VICTORIA, IS A PHONE INFORMATION SERVICE DELIVERED BY MS AUSTRALIA - ACT/NSW/VIC FOR PEOPLE WITH MS. THROUGH ACCESSING THIS IMPORTANT RESOURCE, PEOPLE LIVING WITH MS ARE ABLE TO SEEK EXPERT INFORMATION, SUPPORT AND GUIDANCE TO HELP THEM MANAGE THEIR ILLNESS. A WORKER FROM THE MS CONNECT SERVICE OFFERS US A GLIMPSE INTO HER DAY.

9.10 AM: I took my first call from someone undergoing their diagnosis. They had an MRI scan scheduled and wanted to know everything about MS – especially the symptoms and what a diagnosis would mean for their life. This is a common call, and I was able to chat to them for about half an hour, direct them to our website and send them some information in the mail.

12.30 PM: Just after lunch I spoke to a partner of a young woman living with MS, wondering whether she should be doing any exercise. I told him that exercise was very beneficial for people with MS and referred him to our physiotherapy team.

2.03 PM: I responded to some emails this afternoon, including one about where to get respite for people with MS. Our residential facility at the Studdy MS Centre in Lidcombe (NSW) offers respite so it's great we were able to present this option to this person. Sometimes people with MS and their carers need a bit of a break.

3.32 PM: This afternoon I spoke to a woman who had just been diagnosed. Her neurologist had recommended some immunotherapy, and she had a lot of questions about this. The nurse on MS Connect today spoke to her for about an hour, and made an appointment to go and see her at her house to guide her through how to use her treatment. We also told her about the upcoming newly diagnosed session, where she can meet other people who have just been diagnosed and learn more about the disease. We then referred her onto a Peer Support worker for that extra bit of support.



People with MS participating in a regular physiotherapy class

MS exercise classes: a vital service

ONE OF THE WAYS MS AUSTRALIA – ACT/NSW/VIC HELPS PEOPLE WITH MS THROUGH REGULAR PHYSIOTHERAPY AND STRENGTH CLASSES.

THERE is much evidence about the importance of appropriate exercises programs in maintaining the physical abilities of people with MS. The classes, run by qualified instructors, help people with MS manage their physical symptoms, such as spasticity (the stiffening or tightening of muscles), weakness and pain and to maintain their physical ability, including the ability to walk, as well as they can.

Sarah-Jane Whitfield, who regularly attends classes in the Phillips MS Centre in Chatswood (NSW), says she enjoys the gentle exercises during the classes.

"I find the exercises improve my strength and make me more flexible. My instructor even gives us exercises to practice at home," she said.

We are also partnering with the Heart Foundation and the Diabetes Institute to offer even more classes in more areas for people with MS.

One of our regular exercise class participants, Jill Hodder, was recently the star of Channel Nine's renovation program *Domestic Blitz*, after being recommended by her MS Physiotherapy instructor. Jill's house was radically transformed, including important modifications to help her move around her house.

The thing that meant the most to Jill was the installation of a wheelchair lift which means she can get down to the lounge and study areas – where she has not been for 10 years.

"The lift is amazing," said Jill. "I can now go from the front gate to the back of the house with no problems at all."

"I'm just blown away by everything that has happened."

■ MAIN STORY

MS SOCIETIES MERGE

In a historic move set to directly benefit people with MS, their families, carers and the community, the MS Society of NSW/VIC has merged with the MS Society of the ACT.



MEMBERS of the two organisations unanimously voted to merge the two organisations at recent meetings held in the head offices of NSW and Victoria on 20 June 2008 and the ACT on 25 June 2008.

The Chairman of the MS Society of the ACT, Mr Ian Pennell, and the Chairperson of the MS Society of NSW/VIC, Ms Christina Gillies, said the merge was historic and a testament that the two organisations are committed to delivering enhanced programs and services to people living with MS.

"There will be a range of new and expanded services that will be implemented over the next 3 – 18 months", said Mr Pennell.

Ms Gilles said the Canberra office will become an outreach centre for people

with MS living in South East NSW would be established.

"The ability to share resources and gain access to different skills will deliver a greater number of services to both organisations. We are excited by the opportunity and are committed to providing a better experience for all Australians with MS."

Chairman of the MS Advisory Council in NSW and a person with MS, Brian Lee, said he was excited by the prospect of being able to help even more people living with MS.

"I believe this will help all the societies to continue to provide the best services they can for people with MS," he said.

Another plus of the merge is the efficiencies we will gain through pooling our resources. This will allow us to have a stronger voice when lobbying Governments on behalf of people with MS and streamline our processes including activities like fundraising.

To reflect the ACT coming on board, our organisation will now be known as MS Australia - ACT/NSW/VIC*. You will notice this change over time through our newsletters, events, website and other material you may receive from us. Whilst our name may have changed, the work that we do to support people with MS has not.

This integration shows the commitment from both Societies to deliver enhanced programs and services to people living with MS and we'll keep working together to improve and expand these services.

* Those wishing to donate by cheque or money order to MS Australia - ACT/NSW/VIC should continue to make them payable to "Multiple Sclerosis Limited".

Sydney Water lends a helping hand

SYDNEY WATER RECENTLY PRESENTED MS AUSTRALIA – ACT/NSW/VIC WITH A CHEQUE FOR \$10,000 TO PURCHASE COMPUTER ASSISTIVE EQUIPMENT FOR THE RESIDENTIAL FACILITY AT THE STUDDY MS CENTRE IN LIDCOMBE, NSW.

MANY people with MS are unable to use standard computer equipment due to difficulties using their hands. This donation will buy computer accessories that have been adapted to allow people with MS to use computers more easily, such as flexible mouth piece controls.



Sydney Water presents the \$10,000 cheque to MS representatives

"Thanks to this donation, many people with MS who use the Studdy MS Centre will be given the freedom to use the computers with ease," General Manager of Client Services, Robyn Faine said.

Sydney Water Managing Director Kerry Schott said they donated the funds to recognise the outstanding safety record achieved by Sydney Water staff in the Treatment Operations team.