

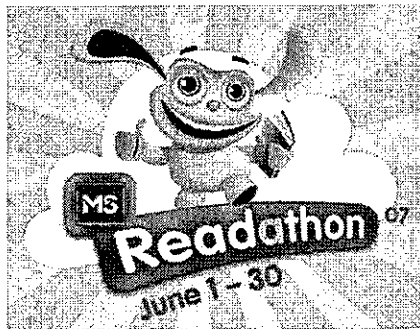


Seeking the Cure.
Providing the Care.

Newsletter of the Multiple Sclerosis Society of the ACT Inc

June-July 2008

MS Awareness Week
2-7 June 2008
See page 5 for details



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General Meeting
June 25, 2008
To vote on the merger with MSL.
Meeting documents to be posted to all members by 2 June.

MESSAGE FROM THE CEO

Robbie Costmeyer

Merger with MSL

Our MS Society is about to embark on a new journey which it started over 30 years ago. On 25th June 2008 members will vote to merge with MS Limited (MSL or MS Society NSW/VIC). The case for the merger is strong; promising an increase in existing services for clients in the ACT region and the addition of some new services which otherwise could not be afforded. Also people with MS in the SE NSW region outside of the ACT, will have better access to services with less travel.

The combined total number of MSL's clients with MS, including our 400 plus clients, will be around 10,000. This larger scale will bring its challenges but a governance structure is being put in place to ensure that our members continue to have a voice at the MSL and MSA Board tables. You will find more information on this in the Explanatory Memorandum being distributed to members in early June.

Each member of the Board urges members to vote in favour of the merger at the General Meeting on 25th June and I too support that view. My prime reason for leaving the position of CEO was for this merger to happen.

MS Awareness Week

This annual "event" or series of events occurs in the first week of June every year. For the past five years the centerpiece has been an MS Symposium held at the Hellenic Club, with local and interstate guest speakers imparting the latest MS information to those who attended. It was decided this year not to hold this event, but a very good program has been devised which I urge members and clients to participate in. *The program of events is listed on page 5 in Swag.*



MS Australia Board

Breaking news is that *Sharon Eacott*, who has been one of our MS Advocates for the past few years, has been appointed to the MSA Board. She was selected from candidates with MS nominated by all of the States and will bring an additional perspective to the policy debates within MSA.

Congratulations Sharon!

30th Anniversary

The Multiple Sclerosis Association of the ACT was formed in 1978 after a number of years of people with MS meeting together as a self-help group and friendship circle. The Society became an incorporated body in 1984. Thus this year marks our 30th anniversary. I had hoped to celebrate this milestone with a formal dinner later this year but the Board decided that the cost of attendance for most people with MS would be prohibitive and opted for a birthday cake instead.



Thus at the conclusion of the General Meeting on the 25th June there will be a light supper and cake to mark the occasion.

Proposed extensions to Gloria McKerrow House have been cancelled

Two more offices and a store room, plus an improved entry foyer into Gloria McKerrow House, were planned to be built mid year. However, no external funding could be found for this project and *a more modest plan is now in place. This plan will convert two existing rooms into an office and storeroom, leaving the Gibson Room available for exercise classes and other Outreach workshops.*

Site Redevelopment

This project is continuing with the appointment of a project officer who will develop a brief to allow three developers to tender, assist with the tender evaluation and represent the Society during the construction phase. The objective is to double the size of our existing premises to enable more efficient operations of the ACT/SE NSW MS Service Centre team and to invite like organisations to join us on site.

Tysabri

The good news is that from 1 July 2008 this new MS drug will be available on the Pharmaceutical Benefits Scheme for people with the relapsing remitting form of MS. This is the first new MS drug for almost nine years and is a welcome addition. A number of oral MS drugs are also in the pipeline and should be available within a few years.

MS Research in Australia

You may recall that MS Research Australia (MSRA) was formed by MSA some three years ago to improve the focus on MS research, engage the best researchers and increase the level of research to develop better treatments and to find a cause of and cure for MS. The good news is that from humble beginnings of an initial research budget of \$0.5M per annum this has grown to \$2.4M in 2007-08 with a target of \$5M pa within a few years. This growth has been achieved despite the fact that the small amount of Australian Government funding, through NH&MRC, is shrinking in percentage terms. MSRA is working hard to address this anomaly.

Last Issue of Swag

This will be the last issue of Swag and I wish to thank the current editors, Rodger and Anne Hall, and all previous editors for their hard work and dedication. It has not been an easy task to produce this newsletter, with contributions often arriving late and the deadline being ever-present. I trust that you, the readers, have appreciated the newsletter.

It is planned that news specific to the ACT/SE NSW Region will feature in the centrefold section of the MSL In Touch magazine, which is a high quality production with a circulation of 10,000.

Farewell

With the impending merger with MSL there will no longer be a need for a CEO in the ACT. I leave the post after over seven years with a sense of achievement and pride, but I will be sad too. I thank the members and clients for their well wishes and expressions of gratitude, I thank the Board for their support and I thank the staff for their loyalty, dedication and hard work. A special thank you too to the many volunteers who contribute so much to the Society.

I plan to be around to finalise the 2007-08 accounts and to hand over to the Regional Manager who is to be recruited soon. My last day is scheduled to be Friday 22 August, the day after the Board meets to adopt the financial accounts.

It has been a privilege working for the MS Society of the ACT and I will miss you all.

I wish the staff a happy and fruitful relationship with MSL and trust that the merger is in the best interests of people with MS in the ACT/SE NSW Region.

Goodbye

BOARD UPDATE FROM THE PRESIDENT

Members of the Board have had a busy year. In addition to performing their normal responsibilities there has been much to be done in looking at the potential of our Society (MSACT) merging with Multiple Sclerosis Limited (MSL), a not-for-profit company limited by guarantee.

MSL is the organisation established in 2006 as a result of the merger of the former Multiple Sclerosis Society of New South Wales and the former Multiple Sclerosis Society of Victoria Limited. Members had an opportunity to listen to a presentation by MSL directors, the CEO and the CFO on 27 February 2008 and to ask questions.

Your Board, having considered the advantages that would be available to people affected by multiple sclerosis in the ACT SE/NSW region, recommends that MSACT merge with MSL effective on 1 July 2008.

It had been planned to hold a *General Meeting of MSACT* in early June to vote on the proposed merger, however, *it is now planned to hold that meeting on 25 June 2008*. This delay will give time for MSL to vary the MSL Constitution to, amongst other things, expand its authority to operate and commit resources to support people affected by MS in regions outside of NSW and Victoria. *Members will receive the notice of the General Meeting, proxy form, member transition form and an Explanatory Memorandum soon.*

If the members of MSACT at the General Meeting agree to merge with MSL, in addition to expanding existing services the following additional services will be made available to expand the range of services, to enhance the specialist skill base delivery to clients and for the education of health service and other service providers in the ACT/SE NSW region:

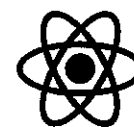
- Neuro-psychology*
- Physiotherapy*
- Occupational Therapy*
- Clinical Psychology*
- Peer Support program*
- Outreach consultants*
- Financial assistance programs*
- 1800 telephone support line*

The proposed transition arrangement of the various categories of MSACT members to membership of MSL will be included in the Explanatory Memorandum.

This is the 30th year since our first President Bill Penson, Margaret Heap and others worked so hard to form the Multiple Sclerosis Association of the ACT from an initial self-help group. The level of support available for people affected by MS has grown enormously since then to what we have today. After the General Meeting to be held on 25 June we are holding a special supper to celebrate and commemorate 30 years of support to people affected by MS in the ACT and surrounding region and to wish the ACT/SE NSW MS service centre well.

Members of the Board invite all members and staff to attend.

MS AWARENESS WEEK



**Activities during MS Awareness Week
in ACT: 1 June to 7 June 2008**

The Canberra Hospital Display

Foyer MS and MS Readathon display at the
Canberra Hospital for MS Awareness week
(Monday 2 June – Friday 6 June).

**Positive psychology workshop
“Building Strengths, Wellbeing and
Optimal Functioning”**

with Amanda Horne,
Friday 6 June, 2 pm to 4:30 pm,
at University House, ANU.

Exercise workshop:



Monday 2 June at 7pm - 9pm,
Gloria McKerrow House –
Presenter: Kym Hirth.

Free workshop for people with MS
and support people. RSVP 6285 2999
by Thursday 29 May.

*How can we help to enhance our wellbeing,
satisfaction and psychological health? Learn about
the latest research and practical strategies from
Positive Psychology, a field grounded in academic
rigour and based on scientific research.*

Continence workshop:

Client and carer free workshop
Tuesday 3 June 10.30am-2.30pm
Gloria McKerrow House
Presenter: Vivienne Van Diesel.



RSVP 02 6285 2999 by Thursday 29 May.

*Positive Psychology is the scientific study of what
builds our strength, wellbeing and satisfaction. The
benefits of boosting our satisfaction and well-being
include: increased health and resiliency, less
anxiety and depression, more energy, engagement
and productivity. This positive orientation infects
others and creates a positive ripple effect, affecting
all who interact with us.*

National Gallery Australia, Turner to Constable Exhibition:

*Special viewing for people with MS and
their carers on Wednesday 4th June at
9:30am, followed by a picnic lunch in the adjacent
Sculpture Gardens. Both the viewing and the
lunch will be free courtesy of the National Gallery
and Café D'Lish respectively. The NGA is a wheel-
chair friendly venue. RSVP 02 6285 2999 by
Friday 30 May for catering purposes.*



*Our guest speaker is Amanda Horne who provides
executive coaching, advisory and facilitation
services to the public, private and not-for-profit
sectors.*

Please RSVP for this event by Tuesday 3 June.
This is a wheel-chair friendly venue. Presentation
includes a tribute to existing volunteers and a call
for new ones and we are asking please for a gold
coin donation for attendees.

*For National Awareness Week information,
please visit www.msawarenessweek.org.au*



Falls prevention workshop:

Client and carer free workshop on
Thursday 5 June. 10.30am-2.30pm
Gloria McKerrow House
RSVP 02 6285 2999 by Tues. 3 June.

Outreach News: Employment issues and MS workshop

An interesting workshop on the issue of employment, discrimination and disability was held on 29th April at Gloria McKerrow House. Staff from the *Disability Discrimination Legal Service* presented on the topic and encouraged people with issues in this area to access the wide range of free legal advice if concerned. *The service provides free legal advice sessions on Tuesdays and Thursdays plus telephone support. Where necessary the service will also provide legal representation in the court system.*

At the session we learnt that the legal view of "discrimination" only applies to cases where services or bodies unfairly disadvantage individuals on the basis of a disability, and not as many believe where an individual discriminates against another person. Discrimination may be direct or indirect (such as in the case of bonuses being awarded to employees who work overtime when overtime is not possible for certain people on the basis of their condition), and is often very difficult to provide evidence for.

The presenters spoke at length about workplace issues for people with physical and mental disabilities.

They emphasized that both employers and employees need to be conscious of making reasonable efforts to resolve issues, and although no one can be forced to disclose a condition, sometimes it can be an advantage for an employee to do so. In certain cases people may be faced with disclosing, or potentially being found to be no longer fit to perform their duties.

Once disclosures are made, workplaces can often modify the environment or workers' duties to allow a more healthy fit between workplace and employee. Frequently these modifications are simple, cheap and effective. Where reasonable efforts are not made to accommodate a worker with a disclosed disability, it is recommended to seek further legal advice.



Welfare Rights and Legal Centre (free legal advice for people in the ACT and SE NSW region)
ph. 6247 2177.

The Disability Discrimination advice lines are open Thursday between 9.30am - 1pm, and Friday between 1.30-4.30pm on ph. 6247 2018.

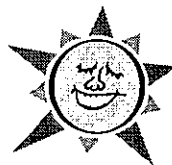
HAPPINESS AND ITS CAUSES

I recently made an investment in my professional/personal development and attended the Happiness and its cause's conference in Sydney. A range of speakers presented on *research findings on the health benefits of happiness, from how to develop increased levels of happiness, to the power of positive emotion and pretty much every thing in between.*

Sessions included; "What makes you happy", "Happiness: developing life's most important skill", "Transforming the emotional mind: challenging the 'happiness set point'", "Unlocking the power of the focused mind and the science of happiness".

And all of this before lunch on day one!

The conference brought together some of my favorite topics, mind body connection, spirituality and wellness, under the gaze and rigor of scientific



research. Research findings were presented about physical and physiological changes that occur in long and short term meditators (e.g. Buddhist monks), the long term increases in wellbeing and the reduced incidence of depression and hospitalisation in those practicing exercises in gratitude, acts of loving kindness &/or regular physical exercise.

Some of the main points I have taken away from the conference are the clear link between the physiology of positive emotion, the relaxation response and its very significant impact on our wellbeing. So, find your happy thought (and dwell in it for a while), it truly is good for your health!

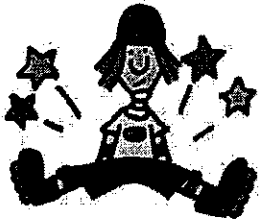
If you're interested in finding out more about the conference, check out the web site

www.happinessanditscauses.com.au

Sue Ellerman

Outreach

Outreach News: Fall Prevention



Have you experienced a trip, fall or stumble in the past 6 months?

Recently had a stay in hospital? Have muscle stiffness, soreness or poor balance? If so, you may be at a greater risk of a fall.

As we age we all find it increasingly difficult to accurately determine distance to and position of objects, and our balance and bodily strength is reduced. People with MS may have such difficulties at earlier points in their lives. It is important to be aware of the potential risks and the wide range of strategies aimed at preventing injury from falls.

There are multiple individual and environmental factors that contribute to an increased risk of falling.

Uneven or slippery floor surfaces, poor vision, inappropriate footwear, poor balance, environmental clutter, inadequate lighting and the effects of medications may all contribute to falls. There is a lot that can be improved upon to lower the risk and an ongoing assessment is valuable because the level of risk changes with changing needs and abilities.

Some things you might consider when attempting to lower the risk of falls include:

- examining floor coverings and replacing any that are worn or slippery with non-slip materials
- reducing environmental clutter inside and outside the home
- ensuring footwear is in good condition and has non-slip soles
- getting regular eye check-ups and using glasses when prescribed
- remove trailing cords and ensuring chairs and beds are at a suitable height
- learning to slow down and recognising the impacts of fatigue on your body
- making the most of mobility aids such as walking canes and frames if appropriate

There are many venues you might explore for assessment and support. An *Occupational Therapist* can assist you in assessing your personal risk factors and provide some useful suggestions to lower the risk. The *Independent Living Centre* in Weston has OTs and nurses on hand to offer advice and a wide range of aids and appliances to give you an idea of what is available (contact ph. 6205 1900). The *ACT Equipment Scheme and ACT Loan Service* can help when purchasing equipment is not an option. (For further information contact the Outreach Team on ph. 6285 2999).

Physiotherapists can assist in setting you up with a personalized program for improving your strength and balance. You might also consider a *personal alarm* such as through the Red Cross (ph. 6206 6040). Alarm systems can provide some peace of mind and an additional level of assistance should a fall occur.

There is also a *free 6 week self-management course* in the ACT for people coping with long-term conditions (i.e. conditions that have lasted more than 6 months such as MS, diabetes, arthritis and depression). This course aims to provide assistance around symptom management, peer support, dealing with difficult emotions, and support around adopting a healthy lifestyle. For further information please contact Janice Stewart on ph. 6287 8099.

In the ACT, *Falls Clinics operate from Community Health Centres and the Canberra Hospital* (to access the falls clinic you can self-refer by calling 6244 3703) and these provide services to people aged over 60 years. For people in need of assessment who are younger than 60 years, they may access assessment and support with a range of health professionals via the *Community Intake Line* (6207 9977).

Thank you to the Falls Clinic staff for providing information for this article.

Samantha Cursley

Outreach News: Wellness workshop series

The first of three workshops on the topic of “wellness” and MS was held on Tuesday 13th May. The Outreach Team takes a holistic view of health and this incorporates not only the traditional physical aspects, but also the emotional and spiritual indicators of good health.

At the first workshop we covered issues around physical wellness and particularly talked about the features of the traditional medical model understanding of health and wellbeing and how this can be complemented very well by the social model.

The social model emphasizes a whole of person approach to health and wellbeing, as well as accepting the broader family, community and society impacts on health. Participants spoke of the importance in identifying “early warning signs” of poor health (such as unusual tiredness, having accidents, and minor illnesses) and of learning to “tune” into these signs and engaging in positive health-related behaviours.

The group also looked in detail at the kinds of strategies that have worked well for them in prevention and management of physical illness. Some of the useful strategies included:

- giving space to acknowledge and feel emotions
- engaging in “dialogue” with your body to assist in prioritizing needs
- physically stopping and resting / sleeping
- using relaxation
- accessing appropriate medications, discussing issues with doctors and other health professionals
- exploring and using other strengths and talents to compensate for real and perceived losses
- utilizing breath-work and focused attention techniques
- massage and other bodywork methods
- counter-irritation and distraction techniques
- asking directly for help and mobilizing supports
- being realistic with ourselves around our needs
- being flexible and realistic with our priorities and self-expectations



The Outreach Team will be holding a further two wellness workshops at Gloria McKerrow House so please join us!

17th June, 3-5pm Emotional and mind wellness

15th July, 3-5pm Spiritual wellness

To RSVP please call (02) 6285 2999.

Samantha Cursley



Fund raising



*Peter Hurford
Fundraising manager*

**Super Choice Raffle 48
Three BMW Models**

We saddle up again for the super choice of three BMWs, (series 3X, 4Z sports or a 523i) but, are facing another challenge of our first ticket price increase.

Ticket selling on Thursdays, Fridays and Saturdays will commence on June 5th at Civic and Manuka culminating with the draw being held at the Southern Cross Club at 6.30pm on June 27th.

Sundays May 25th, June 15 and 22nd sellers will be at the Old Bus Depot markets. We're always looking for more tickets sellers and the last appeal to our members was very gratifying.


Raffle 47 MINI Honda

Following the great success of Raffle 47 MINI HONDA where we all spent a furious 2 hrs selling over \$1500 in the foyer of the Canberra Southern Cross Club, we drew the lucky winner John Paul Dzriba (see image below). John chose the Hybrid.

Again my sincere thanks go to the regular faces who bear the majority of the street selling, which makes the raffles that bit of extra profit



Peter Hurford presenting John Paul Dzriba with the keys to the Honda



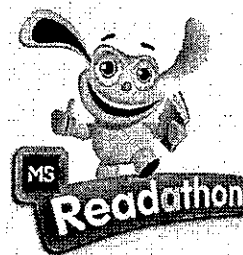
Fun Run Walk 2008
For the first time we will stage the 17th annual MS FRW on a *Saturday: 6 Sept 2008.*
We are communicating with last year's registrants entirely via email and again expect a great response.



Robbie Costmeyer and Peter Hurford with Mr R Stanier, winner of the Advance Buyer's prize.

Xmas Cards 2008
Shortly we will be sending out to you the 2008 Xmas Card Brochure by email as well as displaying the brochure order form on the web site

Readathon



Ready, Set, Go

...the race to register has be-



The National launch of the 29th MS Readathon occurred simultaneously on Thursday, 1 May 2008 across each state and territory in Australia, with the theme this year the Beijing Olympics.

The ACT launch was held at the National Library of Australia and was hosted by Peta Burton of Southern Cross Ten and supported by Education Minister, Andrew Barr. It was a grand success thanks to those who attended and supported the event and thanks to the National Library for donating their space.

Although the size and location varied in each state, the event celebrated the spirit of MS Readathon and provided a consistent call to action: *Race to Register*. The ACT event received attention from the media with a news article in the Canberra Times, and across the radio stations throughout the day.

At the launch, 2007 top fundraisers were provided with gifts including a Penguin book, timer bookmark and a signed copy of Peta Burton's favourite childhood book, Dr Suess' *'Oh, The Places You'll Go'*. Special MS Readathon certificates were presented to our top 2007 fundraisers

As well as the Minister for Education, Andrew Barr and Southern Cross Ten's Peta Burton, the ACT event was supported and attended by MS ACT staff members, MS Ambassador ACT Sharon Eacott, top fundraisers and their families, members of the ACT Children's Book Council (which included teachers from two top schools), ACT Parents & Friends Association, ACT P&C Council, Board Members Ian Pennell and Mary Webb, 2008 community representatives, members from ACT government departments such as the Australian Bureau of Statistics and the Treasury, and the Media Advisor to Minister Andrew Barr.

Currently school visits are progressing well with 80% of those scheduled in the ACT completed, with positive feedback from parents and teachers being received daily. As June 1 creeps closer, when all we will hear is the whoosh of pages turning for the month-long reading period, we are looking forward to a successful year for the MS Readathon.

Children are encouraged to register now to receive their MS Readathon Starter's Pack which includes everything they need to start collecting sponsorship for the books they read this June. Registration booklets can be found at local schools and libraries or even easier, children can register online at www.msreadathon.org.au with the help of mum or dad or call 1300 677 323 for more information.

Indrani Sen
ACT Coordinator,
MS Readathon™

Support Groups

Ideas shared help us all

'Taking Control of MS' group

Thanks to Jennifer Hume, one of our members and a professional counsellor, who spoke to our May meeting about how to manage our own emotional responses to MS. We learned about the ups and downs of MS and, just as importantly, were reminded that there are fellow members and specially trained MS Society staff available to advise and help. (Special thanks to the Society's Outreach Services Manager, Sam Cursley, for coming to our meeting on her day off).

We won't be holding a meeting in June, because our regular meeting day – the 2nd Saturday of the month – follows close on the heels of MS Awareness Week, which runs from June 2 to June 6.

There are good informative sessions planned for Awareness Week, several of which also come within the Taking Control Group's main areas of interest. For those unfamiliar with our group, we focus our meetings on aspects of Professor George Jelinek's approach to managing MS. Broadly speaking, that means we get guest speakers on 4 main subjects – diet, sunshine, exercise, and emotional wellbeing. From time to time we also get speakers who can educate us about the physiology and treatment of MS.

There will be an Exercise Workshop on Monday June 2 and on Friday June 6, Amanda Horne will talk on Positive Psychology. If you heard Amanda at our meeting early last year, you'll know what a good speaker she is and how interesting and relevant her message is. Information about the activities during Awareness is on page 5 of this Swag. All of them come highly recommended.

Our **July** meeting will feature two Canberra chefs, David Bibo and Nick Carter, from the ACT Chef's Network. They will talk about cooking easy-to-prepare tasty meals which George Jelinek would be jealous of. One of our members, Myra Morgan, arranged this meeting (thanks Myra) and it will be a beauty. *So I hope to see you at Awareness Week and our **July** meeting, on **Saturday July 12** from 2:00 to 4:00pm at the MS Society.*

If you'd like to be on our email list, please drop me a line. dcrcanberra@yahoo.com
David Robertson (6295 1210)

People with MS Group

When you're diagnosed with MS, you inadvertently become a member of a club that you didn't want to join! Although initially that diagnosis may be all you have in common, you may find lasting friendships and support through meeting other people with MS.

Why don't you join us? We have both 'old' and 'new' (that's time since being diagnosed, not age !!) coming along, as well a few support people, so it's a nice mix. We're also trialling a "topic of the month", to see if we can entice a few more people to join us, so if you have any issues in particular that you would like to discuss, please let me know and we'll put it on the list. Of course, conversation won't be limited to that topic!

Meetings are held on the last Friday of every month (except December and if coincident with school holidays).

Where: MS Society
Gloria McKerrow House, Deakin

When: 30th May 2008

27th June 2008

Tea and coffee provided, but feel free to bring your lunch.

Relatives and friends are more than welcome.



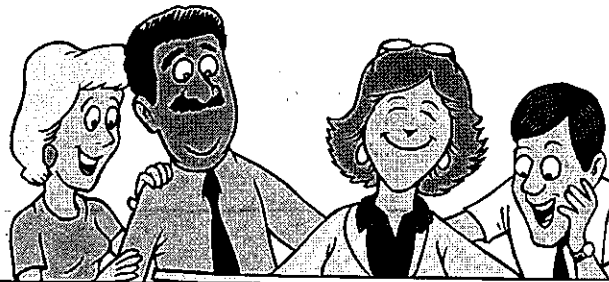
For more information, or if the current timing doesn't suit you, or you have any other input but can't come along, please feel free to contact me, (Mary), by phoning 6251 4502, sending an email to denmar@netspeed.com.au or dropping me a line via the MS Society. At the moment the get-togethers are primarily a 'chat group' but if you have any ideas for other things we could do, we'd love to hear them.

Looking forward to seeing you then.

Mary Webb (Board Vice-president and PwMS)



*Seeking the Cure.
Providing the Care.*



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