



Seeking the Cure.
Providing the Care.

February-March 2008

Swag

Newsletter of the Multiple Sclerosis Society of the ACT Inc

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**Meeting to discuss
merger with MSL**
See page 3 for details

Congratulations Ian Pennell

Awarded Life Membership
of the MS Society



Slaven Mazda Golf Day
March 7 Gungahlin Lakes
See page 10 for details

Parenting and MS workshop
February 26. See page 4



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Too Hot!!

See page 10 for offer
on Air conditioners
by Harvey Norman

MESSAGE FROM THE CEO

Robbie Costmeyer

I trust that you all managed well without us for the two weeks the Society was closed over Christmas. This was the first time that the office was closed for this period and the staff certainly appreciated the break.

Another busy year lies ahead of us.

* Senior Managers and I are in discussions with our counterparts in the MS Society of NSW/VIC (MSL) to prepare for a possible merger with them later this year. I hope that many of you can attend the General Meeting that is being planned for **27th February** to hear a presentation by a team from MSL on the benefits of the proposed merger. As there will be time allocated for questions this will be an excellent opportunity to voice any concerns that you may have. For those who cannot attend, feel free to send me any questions and I will attempt to answer them.

* I am trying to obtain finance to build two more offices, a store room, and improve the entry foyer of Gloria McKerrow House, before I leave mid year. The extra rooms are needed for additional staff (in preparation of possibly becoming a South East NSW MS service centre), and to set up a dedicated room to cater for meditation and exercise classes during working hours.

* Samantha and her Outreach team have planned a full program of courses and programs for both staff development and MS clients.

And of course, we have our usual workload plus new clients coming to us each week.



MS Treatments

As you would have seen in the last Swag, subject to Cabinet agreeing to its inclusion on the PBS scheme, **Tysabri** should become available in April 2008. People with relapsing remitting MS will then have a choice of one of five drugs to manage their disease. This is the first major new MS drug for some 10 years. Other MS drugs, including oral types, are in the testing pipeline and should become commercially available in the next few years. We also continue to increase our funding for research looking for a cause and cure of MS.

All very positive news!

Raffles

This is our 21st year of car raffles and it is still our best fundraiser. In order to increase our sales and revenue we are continually devising improvements. One such change is to introduce options for the winner. MINI Raffle 47 will offer the winner a choice of either a Mini Cooper or a Honda Hybrid car in the colour of the winner's choice.

BMW Raffle 48 will offer a range of cars including the usual 5 series or alternatively the 3 series (sports car) or 5X series (off road car).

I am also looking at joining Havelock Housing Association in a joint house and land package raffle that could be launched later this year.

Thank you to all the **volunteers** who sell our raffle tickets throughout the year and to all of our other volunteers too.

Your Society cannot function effectively without volunteers. Volunteers are still needed for a range of activities and you are cordially invited to encourage your family and friends to help with these tasks and call our volunteer coordinator, Richard Nadin, on 6285 2999 if you can help.

MULTIPLE SCLEROSIS SOCIETY OF THE ACT Inc

NOTICE OF MEETING and AGENDA



**A GENERAL MEETING of members
will be held on Wednesday 27th February 2008 at 5:30 pm at
Gloria McKerrow House, 117 Denison Street, DEAKIN ACT**

FEASIBILITY OF JOINING MULTIPLE SCLEROSIS LIMITED (MS NSW/VIC)

In a the letter dated 28 August 2007 members and staff of the Multiple Sclerosis Society of the ACT (MS ACT) were advised that the MS ACT Board had agreed to explore the feasibility of joining Multiple Sclerosis Limited (MSL). At the Annual General Meeting held on 31 October 2007 an opportunity was given for members to ask questions about the proposed merger and those that attended were supportive of the move, subject to the retention of some local autonomy and local representation at MSL Board level.

A progress report was provided in a joint message from the MS ACT President and MS ACT Vice-president in the December edition of MS ACT newsletter 'SWAG'.

This General Meeting on 27th February provides an opportunity for members and staff to hear a presentation by the Chief Executive Officer of MSL and two of their Board members to outline the advantages of MS ACT joining MSL, provide an update on the proposed merger arrangements and the potential for growth in services to clients in the ACT region. This should facilitate member discussion and establish whether proceeding is desirable.

There will be an opportunity to ask questions of a panel comprising Christina Gillies (Chairman MSL), Paul Murnane (MSL Board member), Bill Younger (CEO MSL), Ian Pennell (President MS ACT), Mary Webb (Vice-president MS ACT), Robbie Costmeyer (CEO MS ACT) and Garry Coster (CFO MSL).

Taking the outcome of the general meeting into account plus all other relevant issues the MS ACT Board will make a recommendation on the proposed merger to members at a duly convened General Meeting of MS ACT in March/April 2008. The final decision to merge or not will be made by MS ACT members. If the decision is in favour of a merger it would take effect on 1 July 2008.

AGENDA

- | | |
|---------|---|
| 5:30 pm | Welcome and introduction by Ian Pennell AM |
| 5:45 pm | Presentation outlining the advantages of MS ACT joining MSL, provide an update on the proposed merger arrangements and the potential for growth in services to clients in the ACT region, by Christina Gillies, Paul Murnane and Bill Younger |
| 6:45 pm | Question time |

A light supper will be served after the meeting.

Please RSVP by Friday 22 February by calling the Society on 6285 2999.

RADM Oscar Hughes AO RAN (Retd)
Secretary
28 January 2008

Outreach News



What's on in Outreach?

Always seeking to improve services for clients, the Outreach Team have been busy planning events for the coming year. The following is just a taste of what you might want to participate in during the first four months of 2008.

January

No workshop

February

Parenting and MS workshop -
Tuesday 26th February, 10am-12pm,
Gloria McKerrow House

March

Newly Diagnosed information night -
Tuesday 11th March, from 5.30pm,
Gloria McKerrow House

April

Employment issues and MS
Tuesday 29th April, 3-5pm,
Gloria McKerrow House

So, why don't you come along and join us?

If you are interested in any of the workshops or information sessions, please register your intention with a member of the Outreach Team.

Samantha Cursley
Outreach Services Manager

We want to hear from you!

It is very important for the continuing improvement of outreach services to learn from you, the clients, what we do well and what we need to do better.



All staff at the MS Society aim to work in a way that is consistent with the agency values, which are :

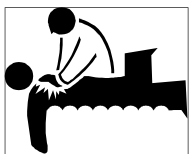
- Care and Compassion
- Respect
- Honesty
- Commitment

We welcome all sorts of constructive feedback, both flattering and not so flattering, and it's very easy to do! Anonymous feedback can always be slipped quietly into the suggestion box that currently sits in the Overall Room next to the card display.

Feedback can be sent to the Outreach Services Manager via email (scursley@ms.org.au) or, you can always provide feedback in person to any staff member or member of the Society Board.

So please, if you have something you want to get off your chest, consider letting us know about it!

Samantha Cursley
Outreach Services Manager



MESSAGE THERAPY Price Increase

Many members enjoy the massage therapy services from

Glenda Ible, Verlie Kennedy, Marion Kain or Christine Godshalx to relieve pain, stress and, in some cases, to restore function. The MS Society offers financial members one massage therapy session per month on a subsidised basis, with members paying around 50% of the cost. For those with private health cover, the cost of the massage therapy session may be claimed back, up to a set limit per year.

Prices for this service have not increased for almost a year but, following a cost review, it has become

necessary to increase the price. Thus effective from 4th February the price of a "one-hour" session at Gloria McKerrow House and at member's homes will rise to \$30, half hour \$20. The price of a half-hour session for a member in a nursing home will increase to \$15, and a one-hour session to \$20.

If any members have difficulty in meeting this increase would they please advise me.

For bookings, contact Richard at the MS Society on 6285 2999 but be aware that places may not always be available for times that suit you.

Robbie Costmeyer
Chief Executive Officer

Family Planning, Parenting and MS

For many people an MS diagnosis coincides with a time of life when issues of family planning and parenting are major considerations. People often ask themselves things like “am I well enough to have a child?”, “what happens if my health declines?” and “can I be a good parent?” Asking these questions is common and answering them is a very individual experience but not one that anyone need sift through alone.



Illuminating some of the myths around these questions may be of some help.

Common myths:

- *If you have MS you shouldn't have children*
Prior to the 1950s women with MS were advised by their doctors to not have children. These days the decision is complex and must be based on individual circumstances. If you are feeling reasonably well there may be very little issue with having a child.

- *MS reduces fertility and ability to conceive*
Researchers have not found a direct impact of MS on ability to conceive. However, there may be other factors that have indirect impacts such as reduced sexual drive making conception more difficult.

- *MS will cause a relapse during pregnancy*
Current thinking is that MS symptoms actually tend to stabilize over the pregnancy period, with many experiencing improved well-being. The flip-side of this is an increased chance of exacerbation (around 20-75%) in the first three months post giving birth. An indicator of the level of risk is the frequency of exacerbations prior to the pregnancy, so as always, personal history of symptoms is the best guide.

- *I will be passing on my MS to my children*
There is a slight increase in risk of 3-5% for a child of a person with MS to go on to develop MS themselves. There is no test at the current time to determine whether or not a child will inherit susceptibility to MS.

- *Pregnancy will alter the long-term prognosis*
There is no evidence to suggest that pregnancy has any long-term impact on the course of MS.

- *A parent with MS hasn't got the energy to effectively parent*

Parenting is often challenging and caring for a baby is a 24 hour a day, 7 day a week job. During the first few months after the baby is born there are likely to be many sleepless nights, worries and anxieties about whether or not you are doing things “right”, a poor sense of routine (what routine?!), and these stresses can create tension between couples as well. It is important to accept that these things will occur and to muster up as much support as possible and conserve energy where you can. Remember that even if you don't have much family support, there is a lot of community-based support available for one-offs or as an ongoing resource (speak to an Outreach Team member).

“The important thing is to provide children with a secure and loving environment in which to grow. Sometimes this can mean being creative and thinking about other ways to support your children to participate in the activities they enjoy”
(Knowledge is power, Volume 10).

Ongoing supports from the Outreach Team

There are naturally many other things that become issues once children are old enough to wonder about your symptoms and why you might do things a little differently from other parents. The Outreach Team has some wonderful resources to assist you in communicating about MS with children of all ages. The Team is available for people with MS, their support people, relatives and young carers. There is free counseling at the Society for children experiencing specific issues around MS. The Team is also able to help examine specific parenting issues from a non-judgmental perspective, and to help you to develop personalised management plans.

For further information please speak with a member of the Outreach Team or even consider coming to the

**Parenting issues and MS
workshop on 26 February.**

Samantha Cursley
Outreach Services Manager

References

Booklet - MS: Its impact on your emotions and lifestyle
Knowledge is power, Volume 10

Support Groups

Ideas shared help us all

Taking Control next meeting

Saturday 9 February

Hi everyone

The good news is that our next meeting on Saturday February 9 should be a beauty. Our presenter will be **Buddhist nun Ani Lhamo from the Tibetan Buddhist Society of Canberra** (www.sakya.com.au).

A few of us went to one of Ani's meditation sessions in November with the Chronic Fatigue Society. Ani's approach is a lovely combination of practical and engaging. She includes mild exercise in her presentation, and she is keen to make sure her exercises suit people with limited mobility. And if you're interested in taking things further, you'll see on the website that the Buddhist Society teaches longer courses on mindfulness and meditation.

Meanwhile, we are unusually well organised at the start of this year. One of our members, Myra Morgan, has arranged with her massage therapist, Gregory Barnes, to give a *talk and a demonstration of Shiatsu massage/yoga at our March meeting. That will be on Saturday 8 March.* Thanks Myra. But before then I hope to see you between 2:00 and 4:00 on Saturday 9 February at the MS Society for Ani Lhamo's presentation. I'll send out a reminder a week or two before the date.

Happy New Year

David Robertson

*Write for Swag
yes, you can!*



Do you have a list of things that you wish you had known earlier ???

ALL OUR MEMBERS

NEED THAT INFORMATION!!!!

*Tell me and I will put it in Swag,
and then everyone can benefit.*

Rodger Hall, Editor

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).

**Where: MS Society
Gloria McKerrow House, Deakin**

When: Friday 29 February 12.30pm

Friday 28 March 12.30pm

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)



Yoga classes at the MS Society

Starting 6th February



*Our next term of Dru yoga commences Wednesday 6 February 2008 at the MS Society, 117 Denison St Deakin at 5:45pm for a 6pm prompt start, classes finish at 7:30pm. Our program is flexible and people **can** attend on a casual basis. Cost is \$15 per class, (some concession available for people on low income).*

Dru yoga is a very gentle flexible style of yoga. Modifications of postures can be applied so that the full benefit of yoga is experienced by people with varying levels of ability.

Michelle Miles, who attended our Dru yoga throughout 2007, writes;

“On Wednesday evening I am a part of a small, dedicated group who gather at the MS Society to practice Dru yoga.

As a busy mother of two boys, I often struggle to find the time or place for a quiet moment. Dru yoga on Wednesday evenings is my time out from this busy pace. It’s a gentle form of yoga with a number of movements leading up to each posture. It is not a strenuous or a high impact workout, however my body feels it has exercised.

Amongst this group there is feeling of friendship, peace and harmony. We are not worried how we look or if we can complete the movements with the grace these beautiful postures deserve. Most of us have MS and can have trouble with balance, fatigue or movement. In our group this doesn’t matter, we are not comparing ourselves, we are achieving what we can manage and sometime that may be only visualizing the posture.

Looking back I believe that I had lost the art of relaxation. With Dru yoga I can relax my mind and body. It is now part of my routine and along with healthy diet, walking and swimming, I am starting to feel well again.

I am thankful for our teacher, Elita, and her dedication to this group.”

Fitness to Drive

Assessing Fitness to Drive for private vehicle drivers

Medical Standards for Licencing Your Questions Answered



- *What are your legal responsibilities if you have a Neurological disorder?*

All States and Territories in Australia have laws about reporting health conditions that may impact on your ability to drive safely. These laws have been created to protect public safety.

The laws require you to report to your Driver Licencing Authority any permanent disability or illness that is likely to affect your ability to drive safely.

This is a grey area and open for interpretation but your doctor is able to advise you on whether or not you should be reporting a condition to the Licensing Authority. When you report your illness it doesn't necessarily mean that your licence will be taken away. It does mean that the Driver Licencing Authority can work with you to manage your condition with respect to your driving

- *What if your condition is only temporary?*

Many temporary conditions will prevent you from driving.

In these circumstances your doctor will advise you about the changes with driving in the short term. In

most cases your licence status will not be affected.

- *How will your doctor assess whether or not you should be driving?*

When assessing your ability to drive safely, your doctor will consider your physical and mental health. He or she will refer to a book of medical standards which is used by all doctors and which describes specific requirements for various diseases and conditions.

- *What is a conditional licence?*

In most cases, having a medical condition will not stop you from driving as you can be issued with a conditional licence. This means that you may continue to drive as long as certain restrictions are met. Conditions may include driving during daylight hours, the wearing of corrective lenses when driving or attending your doctor for a periodic review. Modifications to your vehicle or changing to an automatic car may be a condition. Your doctor may make recommendations to the Driver Licencing Authority about a conditional licence **but the Authority will make the final decision.**

For further inquiries contact the MS ACT Outreach Team on 6285 2999

Reference:

1. Austroads National Transport Commission
Assessing Fitness to Drive
2. Medical Standards for Licencing 2006
3. www.austroads.com.au



Improved Air Conditioning Offer

HARVEY NORMAN FYSHWICK store has just agreed to offer STAFF PRICE to financial MS Society members on all air conditioners, whether it be a fixed or a mobile unit, if purchased from their store at Fyshwick. This offer is also extended for Evaporative portable units in their CLEARANCE CENTRE. There is no need for an appointment as long as customers can verify themselves as MS Society members. The MS Society ID card would be suitable for that – contact the Society on

6285 2999 to organise one (you will need to bring a passport-size photograph).

Michael Scrivener of M&R Air (0413 948 779) is prepared, free of charge, to advise on what size and type of air conditioner would suit your individual needs, to provide a no obligation free quote on any installation and has offered a 15-20% discount to members for installations.

Helena Paul and Robbie Costmeyer

News and Views

Life Membership

Congratulations to Mr Ian Pennell AM.

In December **Life membership**, for his services to MS, was conveyed on Ian Pennell AM by our co-patron, Senator Gary Humphries. This is only the 13th such award made by the MS Society since its inception in 1978.



Members Christmas Luncheon

Members and staff and guests MP Annette Ellis, along with our Co Patron, Senator Gary Humphries came together for some festive cheer on 4th December.

MP Annette Ellis wishes MSS seasons greetings and praises the work of the Society



Helena Paul, and the late JUANNE SWIFT



It's Bon Bon time again



Members enjoying a chat at the Christmas celebrations.



Thanks go to the students of our neighboring Woden School of Hospitality, who provided excellent service

Take a Bow!

Friendly board director Jim Quick serves Vice President Mary Webb and Sue Ellerman (Outreach Team).



Volunteer's afternoon tea

Ever-ready volunteer Julie Mathews takes a break from selling raffle tickets at street booths to enjoy the afternoon tea held in December.



Fund raising



*Peter Hurford
Fundraising manager*

Volunteers! “Take a bow”

I’m sure all of our hard working volunteers were looking forward to the Christmas break as much as the writer was! The months leading up to the festive season were peppered with big asks of volunteers from myself, Robbie and Richard. You all responded magnificently and of course you know we cannot grow the MS services without fundraising.

Thank you to all volunteers.

You are the backbone of our fundraising program for this Society and without you we could not raise those extra dollars that employ the people who provide those fantastic front line services on offer.

There are two volunteers whom I should mention by name, the first, Sharon Eacott, who worked every afternoon shift at Borders, including the last shift on Christmas Eve and even served our new Prime Minister. The second, Sarah York, who takes on multiple shifts all over the city. She is always happy to cycle to a location to assist in ticket selling and also helps occasionally with data entry tasks in the office. Thank you Sharon and Sarah, both of you are stars!



The Borders Christmas wrapping raised over \$2,500, which is a 400% increase on 2006. Whilst this assignment was a bit pressured, reports were that you all enjoyed the high street location, especially being indoors!

MS Charity Slaven Mazda Golf Day March 7th at Gungahlin Lakes

(with shot gun starts at 0800 and 1300.)



Planning is well under way for our annual corporate golf day and this year we are teaming up with Murray Blair, Club Pro at Gungahlin Lakes Golf Course and Loc Luu, CEO of Havelock Housing Association. Hopefully between us, we can achieve record player numbers and hole sponsors. Anyone wishing to play should contact the MS office to have an entry form sent out or go on line to download one (www.ms.org.au). This is one of our major fund raising and MS awareness raising events so any support with volunteering or playing will be greatly appreciated.

Combined Charities Card Shops

Thanks to all of you who put time into the CCCS at both Tuggeranong and Civic and also thanks to those who filled the breach at short notice.

There was a late rush with two of our cards selling out despite MS cards being at the top end of the price range. We look forward to \$2,000 plus return on your efforts, .



*Barbara Parson Sec of the
CCCS with Annette Ellis MP*

 **Cards and Mah Jong**
On the first Monday of each month several groups of 4 people each gather at the MS Society to play cards or Mah Jong. Cost is \$15 which includes morning and afternoon tea, light lunch with soft drink or wine. Proceeds to MS Society

Time: 11.00am to 3.00pm
Place: Gloria McKerrow House

Why not make up a group and come along for some socialising and recreation.

Contact Mary Nelson ph 02 6258 1739 to discuss details

★★★★★★★★★★★★★★★★★★
 ★ Entertainment Book on sale ★
 ★ See the Insert for details ★
 ★★★★★★★★★★★★★★★★★★

Fundraising Car Raffles

The R46 BMW 523i

Raffle 46 achieved a good return with over 16,100 tickets sold, with 196 bonus tickets issued (1 for 10). This was a good result and featured the highest street sales in 5 years. Both winners were loyal long-term supporters, with 1st prize going to Mrs. Bailey from Captains Flat NSW and the \$10,000 cash prize to Mr. Charles Jones from Kariiong NSW. Both winners have been advance buyers for the last 25 Raffles!



Inge Bailey is presented with the keys to her new BMW 523i by Peter Hurford, Fundraising Manager, Jan 2008

BMW Raffle Ticket pricing Survey

We are still collating the returns but we have over 1100 yes votes so far and only 50 no votes. We hope to have a completed picture later this month which will guide a decision whether to increase the price from \$10 to \$15 per ticket. The \$10,000 cash prize value is also being reviewed.

Raffle 47

THE WORD IS CHOICE AND MORE CHOICE!

Honda Hybrid, first time offered in MS Raffles.



or

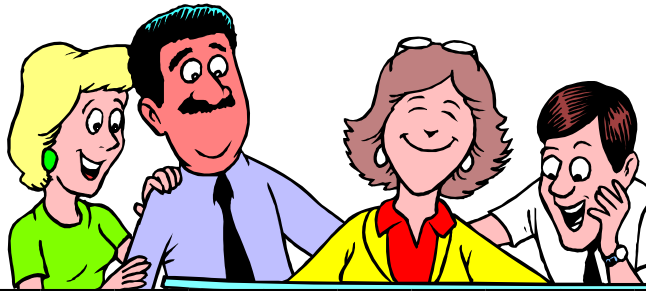


The ever popular Mini Cooper

Whilst MS clients didn't have a choice, we are offering a choice for our latest R47 Mini/Honda Hybrid car raffle. Our supporters will have a choice of either a Mini Cooper or Honda Hybrid (Electric/Petrol combo). The winner will receive a prize voucher to be redeemed at one of two Rolfe Motor Group outlets for a vehicle off the show room floor or, they will be able to order one. This is new thinking in line with giving our raffle supporters more ***choice***. In turn we hope to increase the ticket sales.

Street selling for Raffle 47 will commence on **Thursday Feb 21**, with both Manuka and Civic sites to be booked and one or two Sundays at the Old Bus Depot markets

Don't forget to call up and order some raffle books for selling at your work place. Once again we will have books available to spread the marketing further in search for more sales and it goes without saying we always need new volunteers. Many of the same people are volunteering time after time. It's fun so give it try!



Staff at the MS Society of the ACT

CEO

Robbie Costmeyer

Fundraising Manager

Peter Hurford

Fundraising Assistant

Simon Srbovski

Finance & Personnel Officer

Amy Lee

Office / Volunteer Co-ordinator

Richard Nadin

MS Readathon Co-ordinator ACT

Indrani Raychaudhuri

Web Master

Matt Porritt

Swag Editors

Rodger & Anne Hall

Outreach Services Manager

Samantha Cursley

Outreach worker

Sue Ellerman

Outreach worker

Maria Simos

Immunotherapy Nurse

Helena Paul

Immunotherapy Nurse

Tracy Clark

Massage Therapists

Verlie Kennedy,

Glenda Ible,

Marion Kain,

Christine Godschalx.

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