



Seeking the Cure.
Providing the Care.

Swag


Newsletter of the Multiple Sclerosis Society of the ACT Inc

Gloria McKerrow House, 117 Denison Street, Deakin, ACT 2600

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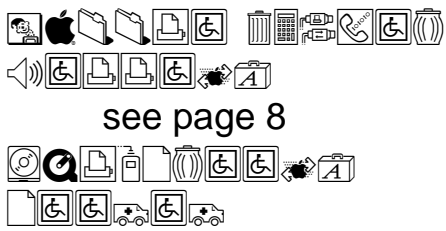
MS Awareness Week
3rd - 9th June
See page 3 for details



- Register for the symposium
- Volunteer's morning tea
- Legal issues Workshop
See page 4 for details

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Friday Jun 15th
Turkish Embassy
7.00pm

MESSAGE FROM THE CEO

Robbie Costmeyer

New Strategic Plan 2007-2009

A new Strategic Plan has been developed by the Board and is now available at Gloria McKerrow House. The Plan is modeled on our Rules and Constitution and reflects the recent client survey outcomes. If anyone is interested in getting a hard copy please see Richard at the Society. An electronic copy has been placed on our website www.ms.org.au.

Staffing

Peter Hurford has recently joined the staff as our full-time **Fundraising Manager** and you will find an introduction written by him on page 8 of Swag. We have made him welcome and I look forward to working with him for some time. For him to be successful, he will need the help of many volunteers and you are asked to continue to offer your services in that capacity please.

Simon O'Dea, our **MS Readathon Coordinator** for the ACT, has settled in well and is busily arranging school presentations

Sell BMW Raffle tickets

A roster to sell **BMW Raffle tickets** has been drawn up and is awaiting your offer to help on days that suit you. Two venues have been selected for "street ticket sales", the Canberra Centre and Manuka. Display cars will be available on both Thursdays and Fridays at both locations commencing on 31st May until 26th June.

Please call Richard on 6285 2999 if you can help.



Funding from ACT Government

Our three-year funding agreement with Disability ACT expires on 30 June and Samantha Cursley and I met with Departmental officials last week to discuss a new agreement. Subject to the ACT Government budget process, which will be announced next month, it seems that the MS Society will receive a new three-year funding agreement.

While this is welcome news, unfortunately there will not be a two-fold increase in funding as requested in the Society's budget submission. Any increase will be limited to indexation of around 3%.

Indications are that the Society is again unlikely to receive any funding from ACT Health for the third year in a row, despite a comprehensive submission for a contribution towards the cost of providing services to people affected by MS.

Volunteering

The volunteer feedback and information session scheduled for 17th April did not proceed as the notice in the last Swag solicited a nil response.

One of the outcomes of the 2006 client survey was that such sessions would be welcomed. The Society desperately needs volunteers for a range of activities. Please encourage your family and friends to help with these tasks and call Richard on 6285 2999 for more information.

MS Awareness Week

Sunday June 3rd to Saturday June 9th

is designated MS Awareness Week and a number of programs have been scheduled. Details appear on page 3 and I urge you all to take advantage of the opportunities to learn and to renew friendships. The centre-piece is the MS Symposium on Wednesday evening and the three speakers should prove very interesting. I hope to see you all there.

June 3^d to 9th

Monday 4th June

Legal Issues Workshop

10:00 am to 12:30 pm at Gloria McKerrow House, followed by a light lunch
Please **RSVP by 31st May by ringing 6285 2999** for catering purposes.
There is no cost for this workshop. See page 4 in Swag for more details.

Tuesday 5th June

Volunteer appreciation awards and planning workshop

10:00 am to 11:30 am at Gloria McKerrow House.
Your feedback on how we can attract more volunteers and utilise those that we have in a better way would be welcome.
Certificates of Appreciation will be awarded at the workshop.

Wednesday 6th June

MS Symposium

5:15 pm to 9:00 pm, doors open at 4:30 pm, at the Hellenic Club in Woden. See Swag insert for more details. This is an annual event which has been well-supported in the past, is great value and always interesting. There is a contribution requested of \$20 pp, which goes towards the cost of the two-course dinner and some wine and fruit juice. There will be a lucky door prize of a dinner for two at the Benchmark Wine Bar in Civic.

Thursday 7th June

MS Dinner

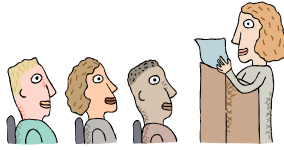
7:00 pm for 7:30 pm at Benchmark Wine Bar at the corner of Rudd Street and Northbourne Avenue. See our website www.ms.org.au for details. There will be a number of items auctioned on the night and the proceeds of that auction will go to F5m for MS Research.

*The **Outreach Team** will have an MS display in the foyer of the Canberra Hospital from Monday to Friday of that week. If you are in the area please call in to say hello.*

Outreach News

Congratulations Helena !

Immunotherapy nurse
Helena Paul has been
 invited to be a speaker at
 the First MS Nurses
 Forum to be held in Singapore on May 18th-20th.



Helena is developing a presentation on
"The Challenges Facing People with MS"
 to focus on MS-related clinical practice issues
 faced by the Outreach Team at the Society in the ACT.

Congratulations on this great honour Helena!
 Watch this space for news from Helena about her
 experience.

Samantha Cursley
 Outreach Services Manager

The MS Society of the ACT
in partnership with
ACT Carers

Invite you to a Seminar on
Legal Issues

10am-12:30pm Monday 4 June

Gloria McKerrow House
117 Denison Street Deakin

This 2½ hour information session will give you information to understand the importance of setting up an Enduring Power of Attorney and a Will. Guest speakers from Legal Aid, Public Trustee of the ACT and Care Financial Counselling Service & the Consumer Law Centre of the ACT, will be available to answer your questions around these important issues.

A light lunch will follow this 2½ hour presentation. For catering purposes, please RSVP to Richard on 6285 2999 by 3pm Thursday 31st May

Sue Ellerman
 Outreach Team

 * **MESSAGE THERAPY FEES** *
 * **HAVE INCREASED** *
 * *
 * A review of massage therapy costs last month *
 * has highlighted the need for an increase in fees, *
 * due largely to a massive increase in the cost of *
 * laundry. Fees have been increased to \$25 per *
 * one hour session, which you will agree is still *
 * very good value. *
 * *
 * Robbie Costmeyer *
 * CEO *
 * *

Counselling

Everything you wanted to know about Counselling (but were afraid to ask).

What is counselling?

(Is it some touchy-feely thing for hippies?)

People have many different ideas about what counselling is, but in essence it is a special way of holding a conversation with a trained professional about things that are troubling you. A counsellor will provide the right kind of environment where you can express yourself, and will assist you in unravelling how you feel and examine possible solutions to the issues you face. Counsellors are trained to listen effectively and help you find the right course of action to suit you. A good counsellor will not tell you what to do and you are in charge of the experience – *your counselling is about YOU.*

Who is counselling for?

(Is it for “crazy” people?)

Anyone, no matter what their age or background, can potentially benefit from speaking with a counsellor. To seek counselling does not mean that a person is weak or lacking in skills. No issue is too “small” and no one has to “soldier on” alone. Something that is a problem for you is important, no matter what other people may think about it.

*Deciding to focus on your issues
is not “self-indulgent”*

– it is an act of caring for yourself and can place you ultimately in a better position to help other people in your life as well.

*When you are well, you contribute to a
healthier environment for others around you.*



How can counselling help you?

(Will a counsellor “fix” me?)

People seek counselling assistance for a wide range of issues.

- Sometimes people benefit from having some help adjusting to changes, either ones that are about to happen, or that have already occurred. This might include creating time and space to grieve a loss – of a loved one, a relationship, a previous role you had, a special time in your life, a pet, a skill or ability.
- Others might appreciate finding some new ways to resolve conflict in relationships – perhaps learning new skills for relating to others.
- Another advantage is the opportunity to share difficult feelings without the worry that you may “burden” someone with them.
- Finally, even when things are going along fairly well, you still may gain from having a different perspective on how to improve your overall wellness and reach your full potential.

Counsellors don’t try to “fix” you because they believe you probably already have the right ingredients to resolve your problems with a bit of help. It may take a number of counselling sessions to work through things, so don’t expect to solve your problems in your first visit.

Counselling at the MS Society of the ACT

Counselling at the Society is free, confidential, unlimited, and open for anyone connected with a person who has MS. Sessions may be

- one-to-one or as a family group at the Society or in a venue of your choice,
- a one-off, or ongoing for a longer period of time.

How you would like to proceed is up to you in negotiation with your counsellor. So why not try it? It’s as simple as picking up the phone, dropping in or sending an email.

Samantha Cursley
Outreach Services

Support Groups

Ideas shared help us all

In a previous issue of Swag
I suggested that you

Write for Swag



Swag is our newsletter and we can share ideas for coping with fatigue or other symptoms, recommendations on scooters/ chairs, how best to time tasks/ work etc., pass on advice for planning holidays, travel or hobby activities.

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
email: Rodghall@ozemail.com.au

Taking Control of MS Group

The 'Taking Control' group meets at the MS Society at 2:00pm on the second Saturday of each month. Named after Professor George Jelinek's book *Taking Control of Multiple Sclerosis*, the group arranges speakers and discussions about ways to maintain their health and wellbeing while living with MS.

Dr Jelinek, who held a workshop for MS Society members in Canberra last year, is a medical professor who has MS himself. He believes that those who follow a strict diet and get regular sun exposure, exercise and meditation, can slow or halt the progression of MS. The MS Society library has copies of Professor Jelinek's book for loan to members.

Everyone is welcome to the group's monthly meetings. Let David Robertson (drcanberra@yahoo.com) know if you would like to receive emails of the group's activities. Or just show up at the meeting.

The group will not meet in June because its regular time coincides with MS Awareness Week. The next meeting will be held on Saturday 14 July.

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 that diagnosis may be all you initially have in common, you many find lasting friendships and support through meeting other people with MS.

Why don't you join us? Share your story, ways of coping, or whatever's on your mind. Or gain a new perspective from hearing someone else's ideas.

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

**When: `` Friday 25 May 12.30pm;
Friday 29 June, 12:30 pm
ie Last Friday of every month (except December)**

- * 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)

Care for Carers



What is a carer? Carers ACT describe carers as “people who provide care and support to a family member or friend who has a long-term physical or mental illness, a disability or who is frail aged”.

A carer might assist in looking after a person full-time or have varying levels of involvement in caring for a person with special needs. The carer may be working in paid employment to some extent as well. They can be a person of any age. Many “carers” don’t actually label themselves as a “carer”

– nevertheless, they put in an enormous amount of work and this can take its toll.

The demands on carers are extensive. Providing support can make it harder to maintain employment, difficult to maintain outside relationships, and it can be physically and mentally draining. Caring for someone with special needs can become so demanding the carer becomes isolated and his or her health can begin to suffer.

Some common feelings carers experience:

Guilt – for not doing “enough”, for getting frustrated, for wanting time out

Fear – of what might happen if he/she takes a break, fear of loss and not coping

Sadness and grief – about the situation and about the carer’s own losses due to their caring role

Love and commitment – to the person being looked after

Carers really need to look after themselves as well

– it doesn’t make sense to keep driving a car that is quickly running out of petrol! *There are a few important things you as a carer can do to ensure you stay in good emotional shape*

Make time for yourself – plan for some mini breaks. Ask around and you may discover people are able to give you a helping hand so you can do a little something for yourself.

Stay social – maintain your friendships. Having contact with a variety of people (both other carers and people who are not carers) is vital to achieving a good balance in life.

Stay healthy – eat regular meals and get enough sleep. Try to stay active, even just a short walk can make a world of difference, not only to your fitness, but it can give you mental “time out”.

Find support – link in with an agency like Carers ACT. There is no shame in asking for a bit of help. There are many carers out there like you, and it can be a relief to speak with other people who know what it feels like to be a carer.

The kinds of support Carers ACT can offer carers:

- Information and referral regarding community services
- Specific information about illnesses or dementia
- Legal and financial information
- Counselling and support groups
- Respite care so you can have a short break
- Practical help with household chores
- Assistance during a crisis
- Support for carers who are also in paid employment
- Access to a library of useful information

Consider making a list of things you would like to know more about – perhaps questions you want answered, or issues you are struggling with. Then, take your list to a counsellor, your GP, Carers ACT or another service you feel comfortable with. Carers need some caring too, and there is support out there if you decide to take the next step.

**Written by Samantha Cursley
Outreach Services Manager**

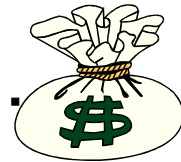
Information on Carers ACT

Website: www.carersact.asn.au

Email: carers@carersact.asn.au

Ph: (02) 6296 9900

Fund raising



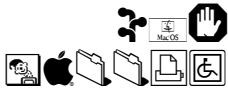
Introducing Peter Hurford Manager Fundraising

I'm delighted to accept the new challenge of being responsible for fundraising for the Society. I'm on a very steep learning curve at present as we promote and market our BMW Raffle 44 (drawn June 27th 2007). The sales are looking strong as I assist in opening the many hundreds of returning envelopes!

My major MS fundraising objectives are to assist in developing new ways to promote existing programs (our four car raffles, our golf day and fun run/walk) as well as working on new fundraising strategies. My role is also to continue to build on the great customer relationships MS ACT has in place along with new strategies of enhancing this loyal base.

By way of background, I have lived in Canberra for 30 years and I'm married to Margaret and have 3 children. I spent a large part of my ACT career as Manager ACT for Allied Pickfords. More recently I launched a \$3 million capital campaign for Little Company of Mary in Wagga Wagga. From 2004-06 I was the Coordinator of ACT Senior's Week involving co ordination of over 60 community groups.

My fundraising mentor Jim Cox said "once you identify people who care about your appeal they will support it in an almost unlimited fashion, because they give with their heart! I'm personally challenged by the continuing need to raise funds for the growing numbers of people with MS with the professional hands-on services here at Gloria McKerrow House. I look forward to meeting many of the MS ACT members in due course. I'm delighted to be on board.



No 44

Drawn 27th June



Car Raffle Ticket Sellers Needed

The major fundraiser for the MS Society is the four car raffles per year, the prize car being a MINI Cooper and BMW 525i alternately. Without the income from these raffles we cannot continue to operate at our current level let alone expand our services to meet increasing demand. We currently have over 400 clients with MS in the ACT region, half of whom are on immunotherapy. This number is increasing at around 7% per annum.

The recently completed client survey highlighted the need for a greater variety of services than is currently available. The MS Society would like to

meet the increasing demand but needs the help of those clients who are able, their friends and their family to make this possible.

We are in urgent need of more volunteers who are prepared to go on a roster to assist with the sale of BMW & Mini raffle tickets at either Manuka or Civic, whichever is more convenient to you, generally on a Thursday and Friday, for the last four weeks before the prize car is drawn. The tickets sell themselves and there is no need for 'spruiking'. Teams of two work a morning shift (09:30 to 12 noon), or afternoon shift (12 noon to 2:30 pm).

Some volunteers are working a number of shifts while, for past raffles, some shifts have had to be cancelled as no-one was available. It would be great if we had more volunteers for this important area of our fund-raising. Some of our sellers bring a personal friend and this is to be encouraged.

If you are able to help please contact Richard Nadin at the Society on 6285 2999.

MS Readathon

Whilst the MS Readathon machine never lays idle, the program was officially launched on Tuesday 1 May, with the assistance of over 400 enthusiastic bookworms at Chapman Primary.

At 12 noon, the students from Chapman started a 5 minute timed reading challenge, at the same time as students in schools all across Australia.

The Timed Reading option will be utilised for the first time in 2007, working **in addition to** the previous model. Whereas previously students were sponsored on a per book basis, they may now be sponsored for blocks of time spent reading, meaning that their favourite large books may now be read through Readathon!

Now in the 28th year of operation, Readathon will again offer students the opportunity to participate in one of Australia's most well-known fundraising program. MS Readathon seeks to enhance the community not only by raising funds that go towards finding the cure and providing the care for PwMS, but also by immersing students in meaningful literacy activities, whilst encouraging them to become mindful social citizens.



For many, Readathon is their first exposure to philanthropy. In this way MS Readathon is one of the few fundraising programs to improve the community both at the end where funds are generated, and at the end where funds are received.

The reading period for 2007 is through the month of June, so if you notice the sound of turning pages replacing the sounds of computer games, you can be certain it's Readathon time!

If you would like your children to be involved in MS Readathon, please visit

www.msreadathon.org.au to register, or call Simon O'Dea on 1300 677 323.

If children known to you are involved in MS Readathon, you may care to encourage them through your sponsorship.

ENTERTAINMENT BOOK

Most readers will have heard of the Entertainment Book but not all of you may realise that this Book is available from the MS Society and has been for some years. The 2007-08 Entertainment Book is available now and you get 14 months of use if you buy it now.

The price is still only **\$50** of which **\$10** stays with the MS Society and is a good fundraiser for us.

Please let your friends and colleagues know that the Book is available here. They can be ordered over the phone by calling 6285 2999. We can send them for a fee.

Richard Nadin
Office Coordinator



Respite Care and The Cottage

Many of our members will be aware that The Cottage adjacent to Gloria McKerrow House was built in the late 1980s, initially to provide respite care for people with MS and related neurological diseases. Unfortunately, the MS Society was not successful in securing ongoing funding to provide for carers to work in The Cottage and for many years members using The Cottage had to arrange for their own carers or have care services arranged by the MS Society. In both instances the costs of the care service was borne by the member. As a result The Cottage was rarely fully occupied

Some three years ago it was leased to Carers ACT as a day-care centre for people with difficult behaviours, including dementia. In the last 12 months, Carers ACT have received additional Government funding to provide overnight respite care for their clients. Carers ACT have spent \$53,000 over that time making The Cottage more “homely” and providing a number of outdoor facilities, including a chook pen complete with chooks.

It is great to see The Cottage now being fully utilised. As well as providing a community service, the MS Society receives a modest income from the rent it receives, which in turn benefits our members and clients with MS. However, on the down side, it has become increasingly difficult over the past year to arrange for our members and clients to take advantage of respite care in The Cottage.

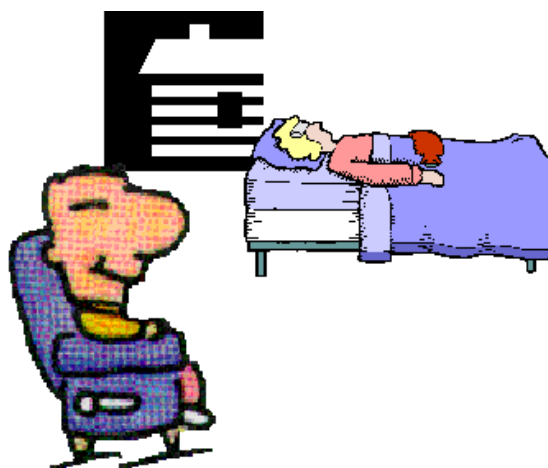
Last month, Samantha Cursley and I met with the CEO of Carers ACT to discuss a more appropriate respite care option for our clients. *It was agreed that given the make-up of the clients currently in The Cottage it is no longer a suitable place for people with MS to have respite care.*

Instead, carers of PwMS are to be advised to call the Commonwealth Carers Respite Centre (CCRC) in Torrens on 1800 242 636 to arrange their respite care. Of course the Outreach Team is happy to be the first point of contact for any questions and is prepared to assist in arranging respite care. Simply call the Society on 6285 2999 and ask for an Outreach Team member.

CCRC will arrange the appropriate respite care for our members and clients, in accordance with the Program’s Guidelines. Carers may be asked for a contribution.

I think you will agree that this is a good outcome and I encourage carers to avail themselves of the opportunity for a break on a regular basis or planned basis. Carers need to look after themselves in order to better look after their partner or other family member with MS.

Robbie Costmeyer
CEO



Volunteers

Multiple Sclerosis Society of the ACT

Can you help us? The MS Society needs volunteers for a huge range of tasks both in-house and at external fundraising functions such as the Golf Day, Fun Run etc. Some, such as selling tickets for the car raffles, involve a 2.5 hour commitment; others are as flexible as whatever time you are able to give. Most of the volunteer jobs have no skills requirement other than a friendly disposition and a willing spirit, however training is available for any specific task that you may be unfamiliar with.

In-house volunteers are needed for:

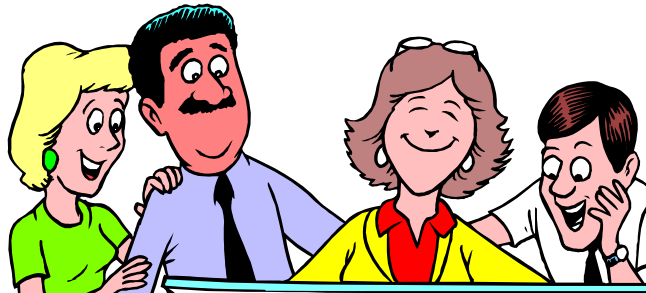
- 1) *reception* – phone, messages, appointments, general administration tasks, course lists etc.,
- 2) *Readathon* – phone, packages etc., assist with general Fundraising Office tasks,
- 3) *mail outs* – tickets, advertising, donors, research materials, Swag, and other occasional seasonal tasks such as packaging and mailing Christmas card orders.

External – volunteers are needed for:

- 4) *ticket selling* – either morning or afternoon in Woden, Manuka or Civic,
- 5) *shopping* – either accompanying the shopper or shopping from a list,
- 6) *transport* – for both wheelchair and mobile members,
- 7) *gardening*, odd jobs, or just dropping in to have a chat and a cuppa with housebound members.

If you can help, please call our Volunteer Co-ordinator

Richard on **6285 2999**.



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

Outreach Services Manager

Samantha Cursley

Outreach worker

Sue Ellerman

Outreach worker

Maria Simos

Immunotherapy Nurse

Helena Paul

Immunotherapy Nurse

Tracy Clark

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