



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

Phone: 02 6285 2999 Fax: 02 6281 0817 E-mail: info@ms.org.au

Website: www.ms.org.au

Take Note

Re-Connect Information Pack Launch (see Page 5)

When: Wed 14 Feb 10.30am
Where: MS Society, Deakin

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Inserts

- Calendar
- Raffle Brochure
- Golf Tournament Flyer



Volunteers Needed in March

Sell raffle tickets for the Mini,
and help at the Golf Tournament
see page 8.

Welcome To staff page 2 and 3 Farewell



Sorry, no yoga till May

MESSAGE FROM THE CEO

Robbie Costmeyer

Client and Member Survey

I spend some time each day to try to stay fit and do promote a healthy lifestyle to others. Therefore I was interested to note that the Client Survey revealed that 72% of clients with MS exercise regularly and 68% had changed their diet as a result of being diagnosed with MS.

Exercise is encouraged and may include walking, jogging, yoga, swimming and/or stretching exercises while seated. Please seek medical advice before embarking on an exercise program.

The Board has requested that I prepare an action list and progress report on the outcomes of the Client Survey and this will be reviewed regularly during the year.

Raising Funds for MS Research

Your local MS Society has budgeted to provide MS Research Australia (MSRA) with \$10,000 in 2006-2007 as our share of the \$500,000 all of the MS Societies will contribute collectively this year.

The planned amount to be spent by MSRA on MS research this year is \$2M, with the additional funding being sourced by MSRA through fundraising, F5M, NH&MRC, ARC and sponsorships.

With the start of a new year, people with MS and their friends are again invited to raise money for MS research in the ACT under the auspices of F5M and I would welcome a phone call from those who are able to help.

Functions could range from holding a BBQ to running a trivia night, for example.

Please call **Richard on 6285 2999** if you would like to help

Volunteer Information and Feedback Day

By way of thanking all of our regular volunteers and to seek their suggestions for improvement a morning has been set aside on Tuesday 30th January. The opportunity will also be taken to provide information and feedback on the various events and activities volunteers assisted the MS Society with throughout the year and to plan for 2007.

More volunteers are needed in a number of areas and if anyone would like to volunteer their services in 2007 please call Richard on 6285 2999

National advocacy drive to introduce new MS treatment on to the PBS

(Based on article in Intouch Magazine, Summer 2006)

The first new treatment for MS in eight years, Tysabri, is now available in the US and Europe and has recently been approved by the Therapeutic Goods Administration (TGA) for use in Australia. However, it was rejected in early November by the Pharmaceutical Benefits Advisory Committee (PBAC) as a treatment to be subsidised for people with MS in Australia.

Some members may recall that the MS Societies were involved in lobbying politicians for the addition to the PBS of the current range of immunotherapy drugs some nine years ago and we are involved on this occasion too, this time to have Tysabri added.

However, the PBAC process is complex and lengthy and it will take at least another six months before a decision is made. Watch this space.



Hail and Farewells — details!

Two people left the MS Society in December and two more are about to leave, while one new recruit arrived in December. We are recruiting for three positions at present – Outreach Services Manager, Readathon Manager and Fundraising Assistant.

Farewells

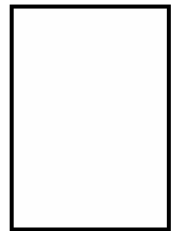
Glenda Tow –Fundraising Manager

Glenda joined the MS Society on 13 December 2004 as the assistant Fundraising Manager. She worked on a number of projects, including MS Readathon, the MS Golf Day, MS Fun Run/Walk and the Mini and BMW car raffles during that time. She was promoted to Fundraising Manager (March 2006) and became responsible for all aspects of fundraising at that time. This is a “full-on” job and, at times, cannot be done solely during normal working hours. *Glenda has done a terrific job and is a person dedicated to the cause of MS as shown in so many ways. She decided to leave the MS Society in November for life-style reasons and has joined Amnesty International. She continues to volunteer her time with us and we wish her well and thank her profusely.*



Teena Cotterill – Data Process Operator

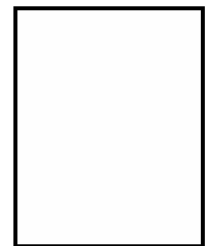
For many years the data processing for the car raffles and direct mail marketing was done by the Fundraising Manager with the help of the Office Coordinator and volunteers like Margaret Rodgers. This workload had been increasing with time so it was decided early in 2006 to employ someone to do this work. Teena was recruited into this new position on 2 May 2006, *worked diligently and efficiently on her tasks until 18th December when she left to pursue a different career path. We thank her too and wish her well.*



Catherine New – Assistant Fundraising Manager

Catherine joined us on 16 March 2006 to help Glenda with the fundraising. She was working with Southern Cross Ten at the time and wanted to work for a cause. She was working up to three jobs in the early stages of her career with us in order to earn enough to meet her needs and despite this difficulty; she was always cheerful, efficient and responsive in her time at the Society. Catherine leaves on 8 February 2007 and is moving to a warmer climate as she cannot bear another winter in Canberra.

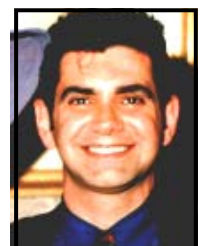
We shall miss her and wish her well.



Welcome

Michael Nasser - Fundraising and Marketing Manager

Michael was recruited into this position after an exhaustive process and was chosen from four excellent applicants. He commenced at the MS Society on 13 December and is our first full-time Fundraising Manager. Michael has an extensive background in working for causes including time with the Australian Red Cross, National Australia Day Council, Austcare, NSW Cancer Council and Smith Family. *He is bright and energetic and is full of good fund-raising ideas. He will be an asset to the Society and is good to work with.*



Please make Michael welcome and if you have any good ideas to raise funds or wish to volunteer your time do not hesitate to call him.

.... And a special farewell to

Sue Donaldson – Senior Outreach Worker

Sue is our longest-serving employee, commencing on 15th June 1998 as an Outreach Worker. She not only is an excellent MS counsellor and advocate, but is also an Occupational Therapist and has helped many clients and staff in that capacity.



Sue has worked with a number of Senior Outreach Workers since she joined the MS Society and on 11 November 2005 she was promoted to that position to succeed Gwen Bartlett.

Sue has been part of a cohesive and effective Outreach team and has lead them well over the past 13 months or so. She is leaving to have a second child and has decided not to come back to the Society when she is eventually ready to return to the workforce.

Sue is well-respected and liked by all staff and clients alike and will be sorely missed. We wish her an easy birth and hope that she will remember the MS Society fondly as she spends her time at home with her family.

GOOD BYE AND BEST WISHES

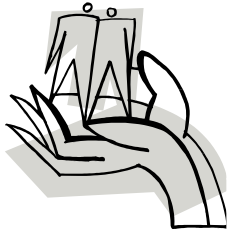
As many of you may know, I will be leaving the MS Society on February 16 as we are expecting a baby around the beginning of April. I wanted to take this opportunity to thank all of the clients for your openness in sharing your lives, sharing your great ideas as to how the Society can operate more effectively and usefully for you, and sharing your energies and efforts in making these changes. I think that I have learnt a lot from each of you, and what I have learnt from one person, has often helped in working with another client. Best wishes in your efforts to manage your MS and in continuing to live productive and happy lives.

I also want to thank everyone I have worked with especially the great Outreach team members, past and present. Your enthusiasm and professionalism is wonderful to be associated with, and it's hard to think of not continuing to work with you to implement the strategies we have talked about both in our informal brainstorming conversations in the hallways and kitchen, and our more formal planning meetings.

Thank you also to the volunteers that lighten our loads here at the Society, and 'fill the gaps' in our clients' lives.

I wish you all well.
Sue Donaldson

OUTREACH NEWS



Re-Connect

Information Package

***Re-Connect** has been developed over the past few months by the MS Outreach Team in the attempt to provide information to people with Multiple Sclerosis who have for many reasons lost contact with the MS Society and may need information on services as their needs change.*

ACT Services and Resources are constantly changing within the Community so we have developed a package of information and will continually update this information.

As people require information The Outreach Team can discuss your needs and provide you with the information about the services and assist you with accessing the services

We would appreciate your input in the future, so if there is services you know about and they are not included in the package please contact us and we will add the information to the **MS Re-Connect**.

Come along & join us for the launch of the MS Outreach Re-Connect Information Package and have a chat & cuppa!

Wed 14th February 10.30-11.30am
ACT MS Society
Gloria McKerrow House
117 Denison Street
Deakin 2600

Maria Simos
Outreach worker

Yoga at the MS Society - 2007

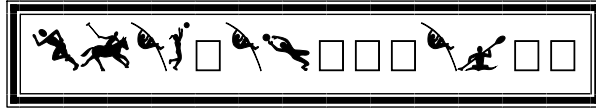
Unfortunately the **first term** of **yoga** for 2007 has been **cancelled**. Elita, our Yoga instructor is scheduled to have surgery in early February. Following the surgery and a recovery period Elita will **return at the beginning of second term**, May 2007, for our Wednesday yoga group at the MS Society.

We wish Elita a speedy recovery.

Sue Ellerman
Outreach Worker

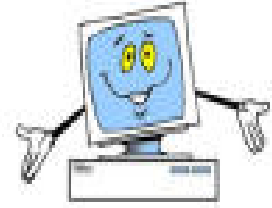


An update on the



The MS Oz Kids website was officially launched on 22 November 2006 and 16 members, clients and their children visited the MS Society and trialled the system.

www.msozkids.com.au



Children of parents with MS often have questions, and the new website has the answers. The website includes Information Pages, News & Events, a 24 hour Message Board and Chat Room. The message board does not operate in real time; children can post their questions and the answers will be posted following approval by the moderators. The moderators are staff from the MS Societies who have been trained in this role.

The chat room operates in real time and will be open for one hour each month. In December, for example, it was open on Thursday 21 over lunch time. Each month, a particular topic will be nominated for discussion in the chat room. December's topic was light and festive, with kids chatting about what they will be doing during the holidays etc.

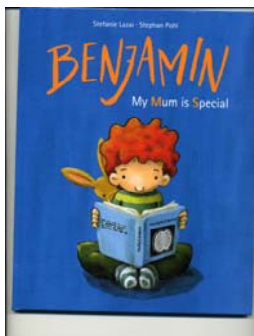
Monitors from the MS Society will be on line when ever the chat room is open to join in discussion and to keep the chat room safe. Users will need to register online and be approved to access the site's message board and chat room prior to entering. These safeguards along with the following rules have been designed to make this site secure for your children's online safety.

Rules for posting messages on our message Board and participating in an on-line chat room;

- Do not include personal information in your messages- no real names, addresses, email addresses or phone numbers.
- No swear words or language that is offensive, hateful, abusive or embarrassing.
- No messages that threaten, bully or intimidate other users of the site.
- Do not send chain letters or pyramid schemes.
- Do not impersonate another person.
- Do not send sexually explicit images or any images that may offend other users of the site.

We encourage children of parents and other family members with MS to access the website as another means of understanding MS and to gain support

*Maria Simos and Sue Ellerman
Outreach Workers.*



BENJAMIN

My Mum is Special

A book for children whose parents are affected by MS, copies are now in the library for your use.

Ideas shared help us all!

“Taking Control of M.S.” Group

On the 13th of January at Gloria McKerrow House, this Dr. George Jelinek inspired group had the sixth meeting of the *Taking Control Group*. A dozen members had a most successful get-together. *David Robertson has provided some informal notes of what happened.*

‘Speaker was Artist Ron Coffey, a down-to-earth fellow and an entertaining speaker, who showed how making art could be fun and accessible for everyone. Our thanks to Ron and to Phillip Smith, who attends Ron's classes and arranged for Ron to speak.

The group then had an open and fruitful discussion about what we wanted from the group and how we should focus our meetings. We were remarkably consistent in wanting the group to focus on the things we could do to help ourselves manage MS and to improve our health and wellbeing. In general, we would like talks from speakers who can focus on the main Jelinek themes of diet, sunshine, exercise, inner peace and personal control of our MS management.

Next meeting, Saturday 10th February, speaker yet to be finalized.

- * *We thought the group’s main focus should be on 'taking control'. While that predominantly meant following a Jelinek lifestyle, it also included other approaches which members found worked for them, and it was valuable in itself to meet like-minded positive people;*
- * *Motivational speakers - someone with workable, practical advice on how to achieve and manage changes in our lives (like diet, exercise and meditation) and how to stay positive;*
- * *More on diet, recipes and practical tips on preparing Jelinek-friendly food;*
- * *A regular session at the end of each meeting when group members can share experiences and advice on treatments, doctors and managing the Jelinek lifestyle;*
- * *Speakers on current MS medical research and research on how people are managing their MS.*
- * *More on meditation, and a regular meditation session’.*

Meetings are held on the second Saturday of each month (except for Dec.), from 2- 4 p.m. General format of the meetings has been to have an invited speaker or activity, afternoon tea and then some time for general discussion

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 may find lasting friendships and support through meeting other people with MS. After meeting a couple of times last year, the PwMS group has decided to make the last Friday of the month a regular time to get together. Why don’t you join us? Share your story, ways of coping, or whatever’s on your mind. Gain a new perspective from hearing someone else’s ideas.

When: Friday 23 February, 12:30 pm
(then same time, last Friday of every month)

Where: Gloria McKerrow House
(i.e. the MS Society in Deakin)

Tea and coffee will be provided, and feel free to bring your lunch. Relatives and friends are more than welcome.

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, I’d love to hear them. Also, if you can think of a better name than ‘People with MS group’ that would be great!!

Looking forward to seeing you then.

Mary Webb

(Board Vice-president and PwMS)

Fundraising Marketing

Michael Nasser

While most Canberrans were out stocking up for the Festive Season and getting the last minute bits and pieces for the holidays, dedicated MS volunteers were in the thick of it raising funds for MS programs and services in the ACT.

From the beginning of 2006 through to the very end, volunteers participated in fundraising events, campaigns and activities and helped raise essential funds which have been directed to support programs such as Immunotherapy, MS Counseling and other Outreach services and Massage Therapy. Our fundraising activities included a Charity Golf Tournament, a Fun-Run and Walk, a Charity Dinner, Christmas gift wrapping and Christmas card sales, and of course the BMW 525i and Mini Cooper raffles.

A huge thank you to all the dedicated volunteers who made our fundraising initiatives successful during 2006. I look forward to working with you throughout 2007

The year's fundraising culminated with the draw of a stunning **BMW 525i** sedan on 16 December. The vehicle, valued at \$116,000, was won by *Jan Finley of Jerrabomberra* and has since been enjoyed by several other members of her family. We extend our thanks to David Rolfe and the team at Rolfe Classic in Philip for their support.



We will be on the look-out for volunteers who are able to sell raffle tickets, in various locations around Canberra in the few weeks prior to this date, as well as helpers for the Golf Tournament.

We have a dynamic fundraising schedule planned for 2007. This year we hope to extend our fundraising across the ACT region in order to expand our reach to members of our local region who live with MS and also need support services.

Enclosed in this issue of Swag, is a brochure and order form for the MINI Cooper raffle and information on our up-coming golf tournament in March. If you are already a Mini subscriber, please encourage a friend or colleague to join. Similarly if you do not play golf, please encourage others to participate.

Remember, we can only succeed with your help, so if you would like to be part of either of these fundraising initiatives as a volunteer or as a participant, please call the office on 6285 2999 to register.



The MINI Cooper Raffle has been launched

and we have an exciting Golf Tournament planned for 2 March 2007. .



If you are already a Mini subscriber, please encourage a friend or colleague to join. Similarly, if you do not play golf, please encourage others to participate.



Multiple Sclerosis International Federation Global Dinner Party



Since 2003, the annual Multiple Sclerosis International Federation (MSIF) Global Dinner Party has united organisations around the world. On the same date supporters worldwide host a dinner party for MS. *The MS Global Dinner Party 2007 will be held on Saturday 24th February 2007. Don't worry if 24 February is not convenient – you can host an event at any time around this date.*

The events can be held for friends, family, neighbours or colleagues and may range from formal catered dinners to casual home gatherings. The event does not have to include food – it could be a

quiz,



play,



concert,



pool party,



BBQ,



trivia night,

etc.



What could you

Instead of bringing a gift for the host, everyone invited to the Global Dinner Party event is asked to make a donation to support the fight against MS. If a tax receipt is required please write down the details (name, address and amount of donation) and the MS Society will then send out a receipt.

After deducting your expenses, the balance should be forwarded to the MS Society with a list of donors who need a receipt, a brief description of your function and the amount raised. Half of the proceeds will be sent to MSA to be consolidated with all of the money raised around Australia and sent on to MSIF for international MS research. The balance will be sent to MSRA for local MS research.

To make participation in this event even easier, the MS Society has a poster that we can then send out electronically to hosts (or provide hard copies if that is preferred) to promote the event and can provide an official letter which you may need to show to suppliers when you are seeking donations of prizes or other goods in support of your event.

Visit the home page of our web site www.ms.org.au to see what people did around the world in 2006 in support of this event and this may give you some good ideas for your event.

Take part and support the MS global movement!

*Robbie Costmeyer
Chief executive Officer*



SERVICES AND ACTIVITIES of the MS Society, ACT

MS Counselling and Support

Available through the Outreach Team for people with MS, their family and carers.

Advocacy

The Outreach Team provides advocacy services for individuals in their community and workplace and represents people with MS through their active community involvement and participation in consultative meetings.

Immunotherapy

The MS Society provides immunotherapy information, training, education and follow-up five days a week by two qualified MS nurses.

Referral to Community Services

While the Society may not meet all your needs we can assist with connecting you to the most appropriate community service.

Home/Hospital Visits

The Outreach Team, including the Immunotherapy Nurses will come to you if you require information, MS counselling, immunotherapy support, advocacy, referral or assistance and cannot come in to the Society.

Accompany People with MS to Appointments

An Outreach worker or volunteer can offer support and accompany you to appointments eg with other community agencies, doctors, the Independent Living Centre, etc. *For maximum use of this service please give the Team plenty of notice.*

Community Education

The Outreach Team regularly conducts information sessions on MS for community organisations. Through community education the Society endeavours to provide community carers with the information necessary to care appropriately for people with MS.

Newly Diagnosed Information Evenings

The Outreach Team provides regular information evenings to people who are newly diagnosed with multiple sclerosis. These information evenings are also open to family, friends and carers of a person with MS.

Respite Care

One bedroom is reserved in the Cottage (bookings essential) for persons with MS requiring respite care. Carers ACT currently operate a Dementia Day Care Centre from the Cottage. For bookings contact Cottage Manager Pauline Dunk (Carers ACT) on 62852082.

MS Identity Card

Some members have reported unpleasant incidents relating to misconceptions regarding their dealing with sharps disposal and when purchasing injectables and related items. Others report that they have been challenged about their right to park in a disabled parking space. One way to overcome these incidents is to obtain an MS Identity Card from the MS Society. (Just provide us with a passport sized photo of yourself.)

Library Service

Approx. 250 books and videos are available for members' to borrow for up to 2 months. No overdue fees apply but books should be returned within a reasonable period for others to enjoy. Leave checkout card with reception. Categories include: MS Information; Diet & Health Care; Relationships & Sexuality; Biography; Mobility & Life style.

Check us out!!



Volunteer Connections

Would you like to volunteer? Or perhaps you need a volunteer? Personal assistance is required for shopping, gardening, appointments or exercises. Volunteers are also need at Gloria McKerrow House to assist with fundraising, newsletter mail outs, selling raffle tickets, the monthly card luncheon, reception duties and data entry. For details, contact the Volunteer Coordinator, Richard Nadin. *(All communication with your volunteer outside the designated volunteer hours is to be through the volunteer co-ordinator or the MS Society.)*

Equipment

Equipment is available at short notice for up to 3 months. We can assist you to find longer term hire elsewhere. Among our equipment are wheelchairs, walking frames, commodes, shower chairs, walking sticks, etc. A \$20.00 deposit is payable on all Society equipment plus a monthly hire charge on most items.

Bridge

Every Thursday from 10.30am to 1.00pm for a fun, non-competitive game of bridge.
Everyone is welcome.

Card Luncheon

First Monday of each month, 11.00am – 3pm, \$15 per person. Play cards and enjoy lunch hosted by MS volunteers. An enjoyable occasion, with all proceeds going to the MS Society.

Therapeutic bodywork/massage

For members; available at the Society and, in certain circumstances, in Nursing Homes and private homes. The Society will subsidise one massage per month - the cost to members is only \$20. Nursing home massage is charged at the rate of \$12 per hour or \$9 per half hour. Private home massage rates are \$20.00 per hour and \$12.00 per half hour.

In providing services to people with Multiple Sclerosis the Society ensures that it complies with the National Privacy Principles



Write for Swag

“ helpful hints were one of the most important sections of Swag ” (from client member survey)

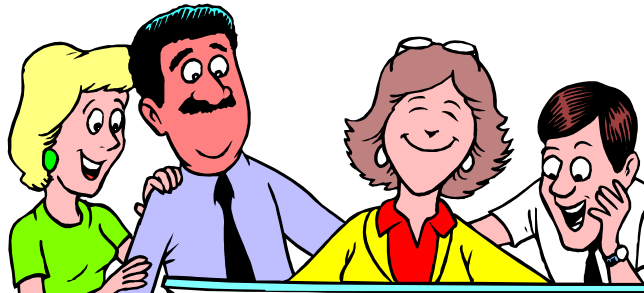
So, what hints can you share?

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 ???

Send details to me and then if I put them in Swag everyone can benefit.

Rodger Hall, Editor



Staff at the MS Society of the ACT

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Robbie Costmeyer

Fundraising Manager and Marketing

Michael Nasser

Assistant FundRaising Manager

Catherine New

Finance & Personnel Officer

Amy Lee

Office / Volunteer Co-ordinator

Richard Nadin

Senior Outreach worker

Sue Donaldson

Outreach worker

Sue Ellerman

Outreach worker

Maria Simos

Immunotherapy Nurse

Helena Paul

Immunotherapy Nurse

Tracy Clark

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