



Seeking the Cure.
Providing the Care.

Dec 2006 — Jan 2007

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

Christmas Lunch

Tuesday 5 December

12.00pm

Gloria Mckerrow House

Book early, ring Richard by Dec 1st.

Details page 4.

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Inserts

Calendar



**HELP
WANTED**

Volunteers Urgently Needed

To:

Sell raffle tickets for the BMW see page 8.

Gift wrapping see page 9.

Christmas Stand down

The MS Society Centre will close on the 22 December and reopen on 3 January

MESSAGE FROM THE CEO

Robbie Costmeyer

Return from India

Some of you might be aware that my wife and I traveled to India in October/ November and upon my return I have met a number of staff, clients and volunteers who have done the same in the past. We all agreed that it was an acute culture shock.

With a population of over 1 billion people and 5000 years of history it is totally different to Australia. In the countryside, people are generally very poor with subsistence farming the norm with a few in each village supplementing their income through some cottage industry. However, they all seem happy with the little they have.

I found the bigger cities very dirty (only Delhi seemed to have public rubbish bins) and the air thick with dust and exhaust pollution with motorized rickshaw drivers racing hither and thither at break-neck speed avoiding collisions by millimeters. There was no obvious obeying of road rules by any of the traffic, except in Delhi where they occasionally stopped at red lights.

Keeping healthy was a challenge every day and each of us in the group succumbed to some malady at least once on the trip

There seem to be no apprenticeships for plumbers or electricians, at least outside the major cities, and the standard of plumbing and electrical wiring was generally very poor and in the latter case, very dangerous, if it worked at all. Brown outs were common. *There were very few facilities for wheelchairs and most of the many monuments (palaces, forts, mosques, etc) involved climbing many, often very steep, stairs.*

I will always remember the colourful and beautiful saris (I never saw two people wearing the same sari), the wonderful monuments, especially the Taj Mahal at dawn and the Red Fort at Aggra, the Dev Dewali Festival of Light at Verinassi, and the frantic bargaining for goods at every turn.



I was very pleased to be back in my own bed and to be able to brush my teeth without using bottled water.

Not a trip for the faint hearted or unfit.

Thank you to Sue Donaldson for looking after business during my absence

Client and Member Survey

Since the last Swag the final report has been received from Tribe Research and distributed to the Outreach Team and Board members. A copy is available in the MS library for clients to browse through.

The overall response was very positive and also provided some great feedback which will be used to plan our Outreach program for the years ahead.

Thank you to all those who responded to this important client survey.

Annual General Meeting

The AGM was held on 11th October and the draft minutes appear elsewhere in Swag.

One of our guest speakers before the AGM, Sarah Ross-Smith, made an impassioned plea for people with MS and their friends, in the ACT, to raise money for MS research under the auspices of F5M.

I am not aware of any volunteers who have come forward since, but I would welcome a phone call from those who are able to help. KPMG has offered to consider applications for some of their staff to help a PwMS to raise funds and there is a small amount of money available to defray any fundraising costs. Functions could range from holding a BBQ to running a trivia night, for example.

Please call the office on 6285 2999 if you would like to raise funds for MS research to develop better treatments and ultimately find a cure.

Opening of the New Outreach Team Offices

Our co-Patrons, Senators Gary Humphries and Kate Lundy, officially opened the office extensions on 11th October. Over 20 members were in attendance and all agreed that it had been a successful project.

Thank you again to the three magnificent sponsors, the J T Reid Charitable Trusts, the BMW Motor Group and the All States Warranty Network, who covered the project costs. Thank you also to the architect, Eric Martin and Associates, the Consulting Engineer, Mike Jefferis, the builder, Carl Olsen of Southside Projects and his sub-contractors. Michael Scrivener of M&R Air installed the air conditioning units.

Members' Christmas Lunch

At the time of writing only 10 members have registered interest in attending this annual event even though it is scheduled for 5th December. This is a wonderful opportunity to catch up with old friends and chat to the staff on a social basis.

Please register with Richard by 1 December to enable suitable catering arrangements to be made.

"Seeing Things My Way"

Daphne Hargreaves, a life member of the MS Society, has published a book of poems which are for sale at the Society for \$20, \$5 of which is retained by us. Daphne read some of her poems at the AGM and this book would make a wonderful Christmas gift.

Christmas Cards, Cakes, etc

These are available from the Society, please call Richard on 6285 2999 or come and visit.

MS Readathon

Despite the setback of reduced participants this year, the higher donations per completer helped to raise over \$4.2 m nationally and over \$158,000 in the ACT. Thank you to Glenda Tow and Catherine New and their team for their hard work in achieving this good result.

BMW Raffle Volunteers

We are still 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 Woden Plaza or at the Canberra Centre in Civic, on a Thursday and Friday.

The tickets sell themselves and there is no need for 'spruiking'. Immediate vacancies are listed elsewhere in Swag so please call Richard on 6285 2999 if you can help with our major fundraiser.

National Advisory Body

Nominations from the ACT region are still being sought (see Oct – Nov 2006 Swag for details). Please call me on 6285 2999 if you are interested.

Christmas Stand down

The office will close on Friday 22nd December and reopen on Wednesday 3rd January.

Merry Christmas to all!



Christmas Lunch

MS Society's Scrumptious Christmas Lunch

Tuesday 5th December,
Gloria McKerrow House, Deakin.



Join us for our annual Christmas lunch to share a traditional meal or a Jelinek-friendly meal, and some holiday cheer. This is a fun and relaxed day full of smiles, conversation and catching up with up old friends.

We hope to see you there, so **book early** with Richard as places are limited for this popular annual event.

Lunch, at 12 noon, is a bargain at only \$15 per person for two courses.

In addition to our friendly staff, both of our Co-Patrons and a number of Board members should be there for you to talk to.

RSVP is required by December 1st by calling Richard on 6285 2999 and please specify whether you want a traditional meal or a Jelinek-friendly meal for catering purposes.

OUTREACH NEWS

Merry Christmas and best wishes to all our clients and your families for a Happy New Year.

Outreach and Immunotherapy services will be available until **22 December**

Services will recommence on **3 January** although with staff holidays there will not be a full complement of staff through January.

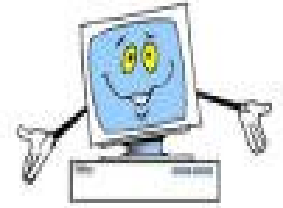
Partial massage services will commence in late January and will be running at full capacity by early February.

We hope that this is a relaxing and peaceful time for you.

The Outreach Team



MS Oz Kids Website



The MS Oz Kids website was officially launched on 22 November 2006.

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.

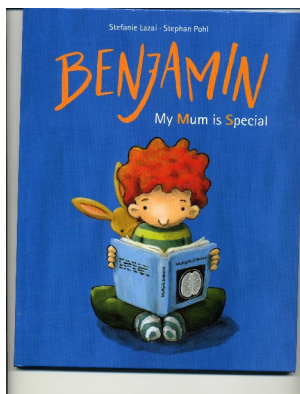
The chat room operates in real time and will be open for one hour each month. In December it will be open on Thursday 21 over lunch time. Each month, a particular topic will be nominated for discussion in the chat room. December's topic is light and festive, with kids chatting about what they will be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



BENJAMIN

My Mum is Special

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

..have a look the next time you are at the Society!

MULTIPLE SCLEROSIS SOCIETY of the ACT Incorporated

MINUTES OF THE ANNUAL GENERAL MEETING Gloria McKerrow House, 117 Denison Street, DEAKIN ACT 6:00 pm Wednesday 11th October 2005

PRESENT

Board members Ian Pennell (Chair), Don Cross, Tracey Cross, Katy Gillette, RADM Oscar Hughes AO, RAN (Retd), Katrina Muir, Jim Quick and David Robertson

Chief Executive Officer and member Robbie Costmeyer.

Life members Daphne Hargraeves.

Members Linda Anchell, Fred Anchell, Sharon Eacott, Paul Gardner, Phillip Gleeson, Rodger Hall, Clive Muir, Jean Pennell, Natalie Sandell, Fred Schinzinger, Les Swain, and Geoff Winter.

Visitor Anita Hargraeves

APOLOGIES

Board members Alan Sims and Mary Webb

Life members Margaret Heap and Dianne Moir.

Members Betty Matthews and Heather Ryan

WELCOME by President, Ian Pennell AM
The President opened the 2006 Annual General Meeting of the Multiple Sclerosis Society of the ACT Incorporated at 6.00pm. He welcomed members and thanked them for attending. He conveyed a special welcome to our Life member Daphne Hargraeves who had agreed to share some of her poems with members during the light supper. The agenda and associated papers for this meeting dated 15th September 2006 were sent to all financial members by 18th September, thus meeting the 21 days notice period in our Rules and Constitution.

The President announced that a light supper would be served after the conclusion of business.

PRESIDENTS OPENING REMARKS

On behalf of the Board and all members the President thanked our generous sponsors, the John T Reid Charitable Trusts, the Rolfe Motor Group and the All States Warranty Network, who together covered all of the project costs for the extensions to Gloria McKerrow House, opened earlier in the evening. He also conveyed the Society's thanks to Eric Martin and Associates (Architects) and Rogers + Jefferis (Consulting Engineers) who donated their time to design the building

extension and to Board member Alan Sims who provided his guidance, knowledge and access to his vast network that made the project possible. He stated that Carl Olsen, the Principal of Southlands Project and his team of staff and sub-contractors had completed the work without fuss and with minimal disruption. He acknowledged the efforts of our CEO, Robbie Costmeyer, for raising the funds and his co-ordination of the project.

The President advised that the sub-committee comprising three life members (Mark Goodall, Margaret Heap and Dianne Moir), formed to consider guidelines for choosing future honorary life members had completed its report during the past year. The Board had noted the report and agreed to adopt the recommended 'Policy on Appointment of Honorary Life Members' in amplification of the provisions of clause 8 of the Rules and Constitution. Within the provisions of this Clause the following guidelines have been included in the policy: *Outstanding service to the Society is defined as follows:*

- *must be substantial and meritorious and have made a positive impact on the Society and its objectives*
- *required commendable personal input*
- *must be able to be corroborated*
- *time or duration of service is not to be considered as a factor in considering the appropriateness of admittance to honorary life membership*
- *the Board may consider recommendations for honorary life membership of present or past paid employees in its recommendations of who might have rendered outstanding service*
- *recommendations for Honorary Life Membership shall be approved by the Board at least four weeks prior to the general meeting of the Society at which the election is to be decided.*

The 'Policy on Appointment of Honorary Life Members' is available for perusal by members if and when required.

AGM cont.

MINUTES OF THE AGM of 12TH October 2005

The Minutes of 2005 AGM held on 12th October 2005 were **confirmed**. (Moved David Robertson /Seconded Jim Quick)

BOARD REPORTS

The President stated that the Annual Report included Reports from the President, the Treasurer and the Chief Executive Officer.

He thanked the Board, for their professionalism, constructive hard work and dedication. On behalf of members, he thanked our Chief Executive Officer and all of the staff who worked so tirelessly throughout the year including those staff members who have left the Society to progress their personal careers. The President especially mentioned Melissa Moore who helped re-establish the funding base of the Society for over seven years and Gwen Bartlett who provided leadership for six years to our Outreach and Immunotherapy Team.

The reports of the activities of the Society, submitted pursuant to clause 34(3) of the Rules and Constitution by the President, the Treasurer and the Chief Executive Officer on the activities of the Society, (pages 2 to 7 of the 2005-2006 Annual Report), were **received** and **accepted**. (Moved Rodger Hall/Seconded Les Swain)

STATEMENT BY THE COMMITTEE (BOARD)

The statement required by Section 73 of the Associations Incorporations Act 1991, signed by the President and Treasurer on 24th August 2006, (page 24 of the Annual Report) and the Statement by the Members of the Committee (Board), (page 39 of the Annual Report) were **received** and **accepted**. (Moved Fred Anchell/Seconded Fred Schinzinger,)

AUDITORS' REPORT

The report submitted by the Society's auditors, RSM Bird Cameron Partners, dated 25th August 2006 (page 25 of the Annual Report) was **received** and **accepted**. (Moved Jim Quick/Seconded Don Cross)

The President pointed out that the Auditors disclaimer on page 40 refers to the detailed Income and Expenditure Statements by functions not included in the Annual Report which are available on request or are available for inspection at the registered office.



FINANCIAL STATEMENTS

The Audited Financial Statements of the Society for the year ending 30 June 2006 (pages 27 through 39 of the Annual Report) were received and accepted. (Moved Sharon Eacott /Seconded Tracey Cross).

APPOINTMENT OF AUDITORS FOR 2006/2007

RSM Bird Cameron Partners were re-appointed as auditors of the Multiple Sclerosis Society of the ACT Incorporated for the Financial Year 2006/2007. (Moved David Robertson /Seconded Katrina Muir).

ELECTION OF OFFICE BEARERS AND ORDINARY MEMBERS OF THE BOARD

The President explained that this is the first year after the changes to the Rules and Constitution in 2004 that only half of the positions on the Board are due for election. In accordance with Clause 21 of the Rules and Constitution two members of the Executive i.e. Ian Pennell and Don Cross and three Ordinary members i.e. Tracy Cross, Katrina Muir and Alan Sims have completed their term.

The President declared the positions of President, Treasurer and three of six Ordinary member positions vacant.

There being only one nomination for the Office of President and pursuant to Sub-Clause 21 (2) of the Constitution, the President declared himself elected to that position for a term of two years.

There being only one nomination for Treasurer the President declared Don Cross duly elected to that position for a term of two years.

There being only three nominations for the three Ordinary member positions the President declared Tracy Cross, Katrina Muir and Alan Sims duly elected to those positions for a term of two years.

MEETING CLOSURE

There being no further business, The President declared the meeting closed at 6.40pm. He invited members to stay for supper and to hear some poems by Life member Daphne Hargraeves.

Fundraising

Glenda Tow

CHRISTMAS:

We have a great selection of *MS Society Christmas cards*

They can be purchased via

- mail order (catalogue included with SWAG)
- in person from the office
- Combined Charities Card Shop, Civic – The Resource Centre, Canberra Museum & Gallery, London Circuit (Tuesday to Friday, 10am – 4pm; 3 October – 13 December)
- Charity Card Shop, The Good Guys Shop, Tuggeranong (Monday to Saturday, 10am – 4pm; 23 October – 16 December)



Also new selections of T-Towels, supper cloths and aprons, which will make wonderful gifts, have arrived - See Richard at the front desk.

Richard will also be taking orders for Walsh's Christmas cakes, puddings and jams. Prices and merchandise will be similar to last year.

BMW Car Raffle:



BMW raffle No. 42 is up and running and **volunteers are still required** to help sell tickets. Thank you to those who responded to the request in the last Swag issue and volunteered their time but, as you will see more are needed to help with our most important fundraiser.

Ticket sales



Kingston Markets

Sat 9 Dec – need two more people

Civic or Woden – **2 shifts; 9.30 – 12, 12 – 2.30pm**

Fri 1 Dec – need two for afternoon shifts at both locations and one for morning at Civic

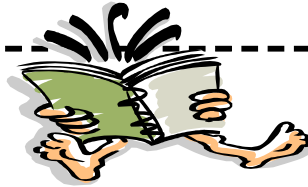
Thurs 7 Dec – need two for both morning and afternoon shift at both locations

Fri 8 Dec – need two for afternoon shift at both Civic and Woden

Mon 11 Dec (two sleeps to go and will be busy) - need two for morning and afternoon shift at both Civic and Woden

Tues 12 Dec (one sleep to go and will be busy) - need two for morning and afternoon shift at both Civic and Woden

Please call Richard if you can help.



MS Readathon:

The 2006 program has wrapped up. Lots of new initiatives were introduced this year and most of them have been successful. Nationally over \$4.2 million has been raised with over \$158,000 from the ACT and approx. \$95,000 from the NSW areas we manage.

Thank you to everyone who has supported the Readathon either by doing school presentations, calling schools or encouraging children to participate.

CHRISTMAS WRAPPING – VOLUNTEERS REQUIRED

The Good Guys & Borders Stores are providing Christmas wrapping for MS volunteers to wrap people's purchases for a gold coin donation.

Proceeds go to the MS Society.

Borders Stores, one of which has just opened in Civic, have an arrangement with the MS Societies Australia-wide for MS volunteers to wrap books for a gold coin donation. It could be an opportunity to form a great relationship with this business locally.

At The Good Guys Tuggeranong we would be part of the Tuggeranong Charity card shop and would share an equal slice of the week's takings of gold coin donations.

I know it's a busy time of year but if you could spend a couple of hours helping that would be fantastic...ask your friends and family!

At Borders Stores, Civic:

Saturday 16th Dec, 10am – 1pm & 1pm – 4pm
2 people required/ shift

Sunday 17th Dec, 10am – 1pm & 1pm – 4 pm
2 people required/ shift

Thursday 21st Dec, 10am – 1pm & 1pm – 4 pm
2 people required/ shift

Friday 22nd Dec, 10am – 1pm & 1pm – 4 pm &
4pm – 7pm
2 people required/ shift

Saturday 23rd Dec, 10am – 1pm & 1pm – 4 pm
2 people required /shift

The Good Guys, Tuggeranong.

Monday 18th Dec , 10am – 1pm
- 2 people required.



Ideas shared help us all!

“Taking Control of M.S”. Group

This group has already had five meetings of people inspired by Dr. George Jelinek and interested in positive action. At the last meeting, it was decided to meet at Gloria McKerrow House , 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

Next meeting 13th January, speaker yet to be finalized.

Future speakers/activities may include a Physiotherapist, an Exercise Physiologist, a Sleep Expert, an Art session with a painter, demonstrations of vegetarian and fish cooking, a Bonsai Expert, Meditation (Jennifer Hume as desired), A Day in the Life of ...? Etc.

What ideas can you put forward— especially if you have a suitable person in mind.

At the last meeting on the 11th of November, Judy Crossen (6288 0768) spoke on Functional Fitness. This humorous, friendly, ball of energy gave us advice and suggestions to help us sit correctly, discussion on rest and sleep, suggestions as to why our bodies became unbalanced, had us agree to drink 6 –8 cups of non caffeine, non-alcoholic fluid a day, etc. etc. etc.

A wonderful session, with expert advice to a friendly group coping with common problems, in a non-threatening cooperative way



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 them to me and I will put it in Swag, and then everyone can benefit.

Rodger Hall, Editor
email: Rodghall@ozemail.com.au



Going on Holiday?

Try Clarke Bay Cottages

These cabins, located at Narooma, have been specially designed to cater for all levels of disability: ramps, wide doors, roll in showers etc.

For detailed information see their website www.clarkebay.com or phone 02 4476 1640.

The Narooma Chamber of Commerce are running a competition with the prize to be 5 nights accommodation for 4 people at Clarke Bay Cottages.

Log on to www.visitnarooma.com.au to see details and put in an entry.

“A Guest Come to Stay!”

Learning to Accept Multiple Sclerosisfrom A Carer

We heard that multiple sclerosis (MS) had come to live in our family. Oh what an unwelcome guest, she would not be gone in 10 days. What a tempest to live with!

Dazed by the diagnosis and prognosis, contact with the MS Society was made. The wonderful people there recommended Dr Jelenik's book. We applied what we could immediately.

We read on, and on about MS until we needed a break. With pins and needles from the waist down we travelled abroad for six or so weeks.

In the last school term of 2005 we enrolled in a yoga class for the over 50s. Gradually meditation entered our daily lives and yoga became the exercise.

At about the same time as starting yoga classes, a range of alternative medicine treatments were accepted.

In October 2005 the Way of the Peaceful Warrior was selected from Jelenik's suggested reading list. We read on and on again, broadening our minds with concepts such as universal laws of spiritualism and healing. These concepts were new to us, but old to the universe. By August 2006 a daily dose of hands on healing was added our healing mix.

Twenty one months after the diagnosis of MS, we have come to accept the presence of this guest. Without her we are unlikely to have met so many gentle and loving people. Nor are we likely to have read so widely or explored alternative therapies or experienced the joys and wonders of meditation.

Daily we have lovingly plied our guest with unconventional therapies. The pins and needles have receded to a small area in one foot.

Perhaps if we loved this guest she would become independent and leave.

SO LONG!

FOUNDATION FIVE MILLION (F5m)

A group of people with Multiple Sclerosis (PwMS) have set up a Foundation to raise \$5m themselves for MS Research. Sarah Ross-Smith is a PwMS in Sydney and is a founding member of F5m. She spoke just prior to our AGM on 11th October to encourage PwMS to set up an Action Team in the ACT. All it needs is three or four volunteers.

F5m Purpose is to raise funds for research for MS cure; raise awareness of MS and abilities of those who have MS; fixed time-frame of 18/24 months, funds raised go directly to MSRA, and there will be a close affiliation with the existing MSRA structure.

F5m Structure is to be led by PwMS, with administration support from MSRA and State MS Societies, Action Team in each State/Territory and a national network for ideas sharing, performance update and publicity.

F5m Status is that all State MS Societies have agreed to assist, an Action Team has been set up in NSW, Victoria and Qld, and an F5m brochure has been developed, PR launch strategy is to be agreed and the agenda/types of events to be agreed.

Challenge of F5m: This is a wonderful opportunity for the empowerment of PwMS through raising a significant amount of money themselves to find a cure for Multiple Sclerosis and to showcase the talents of PwMS.

Please call the MS Society on 6285 2999 if you would like to help raise funds for MS Research

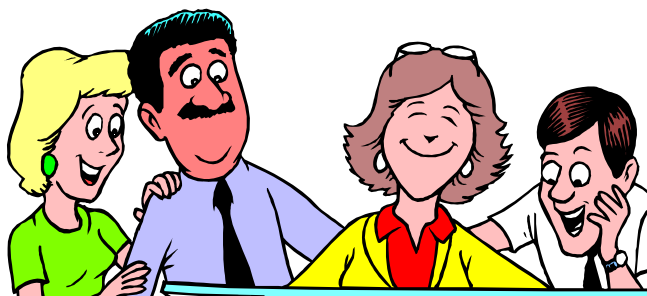
Robbie Costmeyer
CEO





Seeking the Cure.
Providing the Care.

Swag



Staff at the MS Society of the ACT

CEO

Robbie Costmeyer

Fund raising Manager

Glenda Tow

Assistant Fund Raising 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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