



Swag

Seeking the Cure.
Providing the Care.

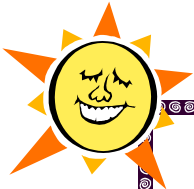
Newsletter of the Multiple Sclerosis Society of the ACT Inc

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

Notice of AGM
31 October 2007
please add date to your diary
see page 3



Thinking about a holiday
See Travel Planning Tips
page 6

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Fun
RunWalk
Sunday 9th September
(page 8)
see you there!

MESSAGE FROM THE CEO

Robbie Costmeyer

MS Awareness Week

During MS Awareness Week in June this year a number of activities were staged by the MS Society to raise awareness of MS in the ACT community. All these activities provided opportunities for people affected by MS to participate and learn. Feedback was all positive.

This year the MS Symposium attracted some 170 participants, well down on previous years. Whilst the feedback from attendees, again overwhelmingly supported this event being held annually, it has been decided that in 2008 we will trial a different format. A committee will develop a new program. Perhaps a series of experts will be invited to speak briefly on their topic and then invite participants to ask questions (i.e. a more interactive discussion involving smaller numbers). To cater for all, we will also trial a range of venues and times, including day, evening and weekend activities.

Suggestions for topics for next June can be submitted to Samantha Cursley at the MS Society.

Volunteering

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

With the help of one of our volunteers, the volunteer database is being cleaned up and rearranged to link volunteers with specific types of jobs that they prefer to do, e.g., letter stuffing, Swag mail outs, raffle ticket selling, helping pwMS (shopping, etc), etc.

This clean up should make “phoning around” more efficient in future.

BMW Raffle 44 Results

In an effort to improve net revenue, four car raffles per year have been undertaken since January 2003. MINI Coopers and BMW 525i cars being offered as first prize alternatively.

The results of the car raffles have been below budget for the past two years however there are signs that this is turning around.

The most recent raffle, Raffle 44, which was drawn on 27th June, did meet budget expectations and this was helped enormously by record street sales.

Congratulations to Peter Hurford, Simon Srbovski, Richard Nadin and the team of volunteers.

MS Readathon

Reading for this annual MS event, now in its 28th year, took place 1 to 30 June and Simon O’Dea, our MS Readathon Coordinator, has met all the targets set of him. Almost 3,600 participants in MS Readathon have registered in the ACT and the three NSW regions also managed by Simon.

Efforts are now being directed towards those who participated but have not yet registered to do so and to collect the money that was raised.

Thank you to those of you who had children participate in MS Readathon and/or sponsored a child. (see page 7)



AGM Notice

MULTIPLE SCLEROSIS SOCIETY OF THE ACT Inc

NOTICE OF MEETING and AGENDA

The 2007 ANNUAL GENERAL MEETING of members
**will be held on Wednesday 31st October at 6:00 pm at
Gloria McKerrow House, 117 Denison Street, DEAKIN ACT**

APOLOGIES:

MINUTES: Confirm the minutes of the 2006 Annual General Meeting held
on 11th October '06.

BOARD REPORTS: Receive the reports of the President, Treasurer and Chief Executive Officer
on the activities of the Society

STATEMENT BY THE COMMITTEE (BOARD):
Receive and consider the statement signed by the Vice-President and the
Treasurer dated 23rd August 2007.

AUDITORS REPORT:
Receive and consider the RSM Bird Cameron Partners audit report dated
23rd August 2007.

FINANCIAL STATEMENTS:
Receive and consider the audited financial statements of the
Society for the year ending 30 June 2007.

APPOINTMENT OF AUDITORS:
Consider the reappointment of RSM Bird Cameron Partners for the ensuing year.

ELECTION OF OFFICE BEARERS AND ORDINARY MEMBERS OF THE BOARD:
Two members of the Executive and three Ordinary Members are due to
retire at this AGM. They will be eligible to re-nominate.

Light supper will be served after the meeting is closed.

By order of the Board
RADM Oscar Hughes AO RAN (Retd)
Secretary
13th July 2007

Outreach News

Carer skill development

Sam Cursley



In the last issue of the SWAG we included an article outlining some of the emotional challenges faced by carers in the community. Some readers may not be aware that the Canberra Institute of Technology have a “Skills for Carers” team who work very hard to develop free training programs for carers around a huge range of issues.

Training programs currently on offer for second semester this year include the following:

- “Challenging behaviours and situations” (for parents)
- “Supporting someone with depression”
- “Senior first aid”
- “Medical emergencies in the home”
- “When caring gets you down”.

The Carer Skills Team aims to provide programs that are responsive to the real-life needs of carers and they are very open to suggestions for new training topics. Programs are offered at the various CIT sites as well as at certain community venues.

For further information about courses and/or to be placed on the CIT Carer Skills newsletter mail-out list, contact ph. 6207 3628 or email CarerSkills@cit.act.edu.au



Low cost internet for people with a disability

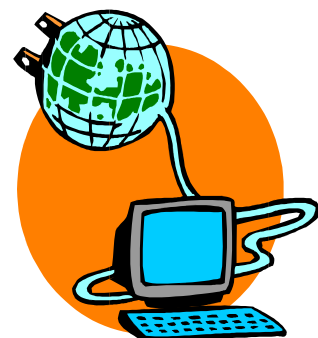
Sam Cursley

Many people who are living on pensions have experienced difficulties accessing and affording information technology. As a response, the national body “Technical Aid to the Disabled Australia” (TADAust) was set up in Sydney nearly 30 years ago to provide low cost technical aids to people with disabilities.

Through local TAD services, people with disabilities, veterans and the frail aged can be provided with technical aids and low cost internet access allowing a level of independence for those who otherwise might be quite isolated.

Normally internet access costs around \$30-\$40 per month; however, for those who qualify, dial-up internet access can be arranged at a rate of \$5.50 per month after an initial \$36 establishment fee. For those currently on the Disability Support Pension, a DVA Entitlement Pension or Aged Pension, this is a very affordable option.

More information on the TADAust Connect internet connection service can be obtained on **1300 735 439** from 9am to 5 pm Monday to Friday, or by visiting the TADAust Connect website: www.tadaustconnect.org.au



Support Groups

Ideas shared help us all

Hello *Taking Control* members

Thanks to our Outreach Services Manager, Samantha Cursley for her talk (Saturday 14/07/07) about how to cope with the effects MS has on our abilities to think clearly. If you want more advice on your own circumstances, talk to Samantha or her outreach team at the MS Society (02 6285 2999).

One of our *Taking Control* members, Samantha (Sam) Wilson, mentioned a website full of specially designed exercises to help your thinking capacity.

Sam says: "Seriously, give this a go. Lumosity (<http://www.lumosity.com/>) - it's a way of training your brain - games deal with improving memory, cognitive functioning, attention, processing speed, etc. It's set up like a very basic computer game/s, which you progress through as you get better at the games. I'm loving it and getting better all the time - it's cool to see how far I've come." The website gives a 14 day free trial, but after that it costs US\$6.60 (about A\$7.60) per month.

Our next meeting will be at the MS Society on Saturday 11 August, and our speaker will be Dr Rex Simmons. Rex runs the Australian MS Longitudinal Study, which many of you probably contribute to (they are the people who post out questionnaires to people with MS every few months).

Rex has a wealth of knowledge about MS and how people with MS live their lives. If you've been to one of his presentations, you'll know how good he is. If you haven't, then come along and find out for yourself next month. Everyone's welcome.

All the best
David Robertson



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. *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 31 August 12:30 pm
Friday 28 September 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)

In previous issues 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

Good Access Makes Travel Easier

Courtesy of MS SA/NT

When planning a trip it is best to plan well ahead to get the best possible information and advice about the accessibility of places you want to stay and places you want to visit.

Think about your own functional level and what supports/equipment you may need. Always plan for the worst-case scenario and prepare around that functional level.

When booking travel always let the travel agent/buslines/airlines/trainlines/ferries etc know if you require wheelchair access or special assistance. There is rarely a problem if they know ahead of time. It is also a good idea to turn up early so there is plenty of time for them to attend to your needs.

Some useful questions for general access:

- * Is there accessible parking?
- * Is there accessible parking with powerpoints for scooters, electric wheelchairs?
- * Are there any steps or ramps or is there level access at all entrances?
- * Is there protection from wind, rain and sun while waiting?
- * Are the doors wide enough?
- * Are the doorhandles lever style?
- * Are there handrails?
- * Are there seats at a good height with arms and backs?
- * Is there good lighting?
- * Are internal and external pathways wide?
- * Is there room to manoeuvre a walker/wheelchair?
- * Are the floors slip resistant?
- * Are the emergency exits accessible?
- * Is there a ramp or lift to all levels?
- * Are the toilets accessible and have rails provided?
- * Is there staff to assist with luggage?

Tourism activities:

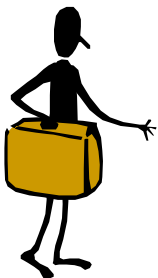
- * Can you get an accessibility map of the area indicating parking, toilets, attractions etc?
- * Are the exhibits suitable heights for wheelchair users?
- * Accessible guided tours, viewing areas, lookouts, rest areas, toilets etc?
- * Accessible boat ramps, jetties or fishing platforms?
- * Is there ramped or decked access to beach areas, swimming areas, swimming pools?
- * Accessible picnic areas?
- * Are there accessible restaurants/eating areas?
- * Is there accessible public transport?

Guest rooms:

- * Are the power points and switches at a good height?
- * Is there access to tea/coffee/water facilities as well as the microwave/oven/fridge?
- * Is there good lighting?
- * Is there an emergency buzzer in the bedroom and/or bathroom?
- * Is there clearance under the bed for a hoist?
- * Is there a ceiling hoist?
- * Can the wardrobe rail be reached from a wheelchair?
- * Is there storage room for mobility aids?
- * Can the curtains or blinds be opened/closed?
- * Are the taps lever types?

Bathrooms:

- * Is the toilet accessible and at a good height?
- * Is the shower over the bath?
- * Is the shower alcove level access?
- * Is there a hand held shower hose?
- * Are there grab rails in the shower alcove and by the toilet?
- * Can the mirror be used from a seated position?
- * Is there access under the hand basin for a wheelchair user?



There are some travel agents who are experienced with disability and are able to plan the whole trip for you, making sure that all aspects of accessibility are covered.

This will give you a start, but however well anyone plans a holiday there are bound to be hitches, upsets and often unavoidable spanners in the works. Successful travel requires a good sense of humour, patience and at times a great amount of self-control. Experience is always the best way to learn, so go out there and start travelling, making sure that any good tips you discover get reported back to your network, so that the information can reach everyone and pitfalls can be avoided.

HAPPY HOLIDAYS

MS Readathon



Students book in for the conclusion of MS Readathon 2007.



School libraries, playgrounds and households have returned to normal, as the reading period for MS Readathon 2007 closed on June 30. Registrations continue to trickle in from around the region.

Over 72,000 eager bookworms from around Australia participated in MS Readathon 2007, reading to help change the lives of Australians living with Multiple Sclerosis.

Students from 136 schools participated in presentations given by one of our fantastic Community Representatives. These engaging interactive presentations aim to educate students on the fundamental aspects of Multiple Sclerosis, and inspire them to register and read for MS Readathon.

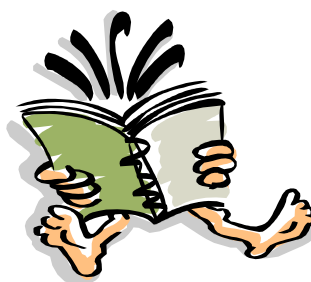
Special thanks must be made to Tracey Bennett, Mollie Bialkowski, Sophie Cooper, Lynette Dickinson, Susan Peters-Smith and Natalie Sambhi, who performed tremendously in the role of Community Representative. In this role, these fantastic individuals act as the public face of MS Readathon, both inspiring children across a wide age range to help change the lives of Australians living with Multiple Sclerosis, and ensuring that the needs of the schools in their regions, which often cover a large geographical area, are met.

With preparations being considered for MS Readathon 2008, members of the public are advised that should they wish to act as a Community Representative in 2008, they can register their interest now with Simon O'Dea on **1300 677 323**.

Of Australia's 10,000 schools, 6,900 made the decision to support the MS Society by participating in MS Readathon. The MS Readathon team visited over 3,000 of these schools, with 3,800 schools electing to receive a reader leader pack. These packs contain registration booklets, posters, and an informative DVD that allows teachers to encourage students to learn more about Multiple Sclerosis and register for MS Readathon.

In 2006, 56,683 students completed the program, raising a total of \$4.3 million for MS Australia. With over 72,000 children registered for 2007, and registration forms still flowing in, 2007 is set to deliver strong results again.

August 30 is the deadline for returning sponsorship funds, so the key message now is that any children who have participated in MS Readathon without registering can still do so, and keep reading and fundraising right up until 30 August! Return forms have recently arrived, allowing those who have completed MS Readathon 2007 to return their sponsorship funds.



Fun Run

MS Fun Run/Walk
Sunday September 9th 2007
10:00am start.

You and your family and friends are invited to enter this year and help us to continue supporting those who are affected by Multiple Sclerosis (MS). Your participation helps to raise MS awareness in the community and encourages keeping fit too. It is the same course as in previous years, which is 6.5km around Lake Tuggeranong and now is as good a time as any to start training.

Participants are encouraged to seek sponsorship for entering the event and the extra money raised from this ensures that we are better able to continue supporting those affected by MS. To assist in this process a range of awards are offered depending on the amount raised. These rewards are shown on the 'Register Now' entry form.



There is no hard copy entry form this year (reducing costs) and you are encouraged to register online with <https://www.registernow.com.au/secure/Register.aspx?ID=577> either directly or via our website www.ms.org. Entry fees and sponsorships are tax deductible and you will receive an instant tax receipt form.

Register Now.

Be an early bird and **return your entry form before August 31st** to be in the draw to **win a Two Night Midweek Package for two at Solar Springs Health Retreat in Bundanoon** (conditions apply).

If you require further information about the event or would like to **volunteer** to help on the day please do not hesitate to call the MS Society on 6285 2999.

Peter Hurford
Fundraising Manager

Yoga is Back



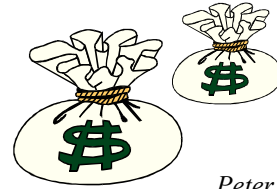
*Our new 10 week program of yoga commenced Wednesday 25 July and continues through until 26 September. Classes start at 5:45pm and finish at 7:30pm. Our program is flexible and people **can** attend on a casual basis. The cost of the program is \$10 p/w for low income earners and \$15 for those in paid work.*

Everyone is welcome to a Dru Yoga morning tea

On Tuesday 7th August at 10:30 am at Gloria McKerrow House 117 Denison St Deakin. This is a great opportunity to find out more about Dru yoga and the classes we run. Elita, our yoga instructor, will be talking about the art and science of Dru yoga and will be able to answer your questions. This will also be a good time to meet and talk to others who have been enjoying our yoga classes.

RSVP by COB 3rd August, for catering purposes, to Richard Nadin at the MS Society on 6285 2999.

Fund raising



Peter Hurford
Fundraising manager

Time waits for no person! Gosh it seems like yesterday, yet it's over 10 weeks since I joined the MS Fundraising team. To use a pun, since then I've had a real SWAG of things to learn about MS and how we run our four great vehicle raffles! We have some exciting future raffle plans ... *watch this space!*

Thanks to Simon Srbovski and to all of the other MS staff who lend a hand from time to time to help the fundraising team. Thank you all for your co operation and understanding during my first few weeks.

Tax Appeal

Our tax appeal is almost closed but so far it has been a disappointing result with donations some 25% down on previous years.

Fun Run

Plans are now afoot for the 2007 MS Fun Run/Walk *to be held on Sunday 9th September*



Invitations have been posted to all 790 previous participants. The event is 6.5 km around Lake Tuggeranong on a flat course. A challenge is issued to those in wheelchairs to enter the event and try and beat Jim and Pat Quick, who are multiple winners.

We are planning to make FR/W 2007 our best yet.

I hope to see you at the fun run/walk at Lake Tuggeranong on the 9th September, either as a participant, spectator or as a volunteer, and I hope that you can help with ticket sales of the MELLOW YELLOW MINI COOPER in Raffle 45!

Car Raffle

BMW Raffle 44 concluded on Wednesday last, both winners went out of the ACT. The BMW was won by Mr Stephen Sanderson of Netherby, SA. Advance buyers prize of \$10,000 cash went to Mr Sabahattin Mustafa of Chipping Norton NSW. Congratulations to both of them and commiserations to all of the others who contributed to the draw. However, I take from a Chinese saying: *"We all won as we had the means to make a gift!"*

My special thanks go to volunteer Ian Pennell for his final ticket control assistance and mentoring in general. With Ian's sound organisational raffle skills we made the deadline.

My heartfelt thanks also goes to all my ticket selling volunteers who braved some of Canberra's chilliest days in June, just past, to help us sell a record number (1918) of BMW tickets. Had it not been for a couple of cancelled days due to rain, we would have sold more than 2000.

Raffle 45

July 12 saw us move onto the "SPORTY MELLOW YELLOW MINI COOPER". I'm pleased to announce that for the first time we are offering a one for five discount ticket! We hope that will give us a great lift in raffle ticket sales.



An image of the car is posted above and on our web site. Raffle 45 will be on the streets later in **August**, so watch this space and your emails!

We will go where no seller has gone before to sell out R45!

Blood and Organ Donation

Written by Samantha Cursley
Outreach Services Manager

Blood and organ donation for people with MS

It is amazing how many people with long term illnesses are still keen to donate so that others might be given a chance for life, or a better quality of living. This is certainly a very admirable activity especially considering that nearly 2000 Australians are awaiting organ transplants and the Australian Red Cross are always seeking new donations of blood.

Recent queries from people with MS regarding blood and organ donation have led to MS ACT staff taking on some research into the issue. This article aims to provide a bit of general advice that may serve as a guide when discussing the matter with your loved ones.

Blood donation

The Red Cross go to extraordinary lengths to screen the blood donated to ensure it is safe for use. This is done particularly because people requiring blood transfusions are normally quite unwell and as such, are prone to infections. In a recent discussion with the Red Cross it was acknowledged that the exact cause of MS is still a mystery, and at this point in time doctors and researchers are unable to rule out a viral cause. Due to this, **blood donations from people with MS cannot be accepted.**

Organ donation

A wide variety of organs and tissue are able to be transplanted including bone tissue, heart valves, lungs, eye tissue, kidneys, pancreas, heart, liver, and skin tissue.

The process for assessing organs for transplantation is a very different matter to that of blood / blood products and there is a particularly great need for organs to be donated. A very specific risk assessment must be undertaken whenever a donated organ becomes available, and this process includes determining viability of the organ given the mode of the donor's death. The advice the MS Society has been given is that people with MS are able to donate their organs, either for transplantation, or of course for scientific research purposes.

It is important to note that universities undertaking scientific research require the person's entire body and therefore if this is a person's wish, none of their organs will be used in transplants. The process of donating for scientific purposes is completely separate to donation for transplants. *Should you wish to donate to science you should clearly define your intentions in consultation with a solicitor.*

Those of you that attended the MS Symposium at the Hellenic Club in June 2007 would have heard Dr Peter Patrikios talk about an exciting new initiative of MS Research Australia (MSRA) in setting up an MS Brain Bank to help find a cure for MS. Dr. Patrikios is the founding Director of the MS Brain Bank and is seeking people with MS to register their intention to donate their brains, and indeed their whole body. *"Researching MS with human tissue has many advantages over research using animal models. These models do not accurately reflect all aspects of MS in people, so using tissue from the MS Brain Bank will accelerate our knowledge and our progress towards a cure",* he said.

Registration details can be obtained from the MS Society on (02) 6285 2999, Dr Peter Patrikios on 1300 356 467 or from MS Research Australia on 1300 356 467 or www.msra.org.au.

Currently, 924,387 Australians have registered their legal intent to donate organs (figure provided by Medicare Australia). *If you are interested in donating organs it is important to register your intention both with loved ones and with the official national organ register.* This is administered by Medicare and is called the "Australian Organ Donor Register". Registration may be completed online via the Medicare website or accessed through the "Australian's donate" website, both listed at the end of the article.

You may also register by visiting your local Medicare office, where you can pick up a Donor Register brochure and registration form or by

continued

telephoning: 1800 777 203. Once registered, you will be given a card identifying you as a registered donor. Information kept on the register is accessible only by select authorised personnel, who have signed confidentiality agreements covering the access and use of personal information. You can change your consent at any time by submitting a new form to the Register.

In the ACT and the Northern Territory, information regarding intention to donate organs is not currently included on driver's licences. Only people aged 18 or over are able to legally register their consent to donate, however, people aged 16-17 years can register an *intent* to donate.

Information kindly provided by:
Australian Organ Donor Register -
www.medicareaustralia.gov.au/organ

The "Australian's Donate" website -
www.organdonation.org.au

Australian Red Cross - www.redcross.org.au

Dr Peter Patrikios FRACP, DMedSci (Vienna)
Director of the MS Brain Bank, Department of
Medicine, University of Sydney.

Visit by Mrs Nola Rawson, National Director, MS New Zealand



New Zealand has a population of around 4 million and a clinical survey is currently underway to determine the number of people with MS. It is estimated that this will be around 4,000. This number would bring the incidence of MS per 1000 to roughly the same as the ACT and Victoria. The South Island of NZ is colder and thus has the higher incidence of MS of the two main islands.

Nola Rawson heads the national MS body in New Zealand and was in Australia at the invitation of MS Australia. She visited MS Limited in Melbourne and Sydney and spent 1½ days with us in July. She met with the President, CEO, Outreach Team, Fundraising Manager, Massage Therapists, Office and Volunteer Coordinator, and one MS Advocate, ie she was thoroughly briefed on our operations.

The MS organisation in New Zealand is very different to how we operate in Australia today. There is one national office of four staff, including

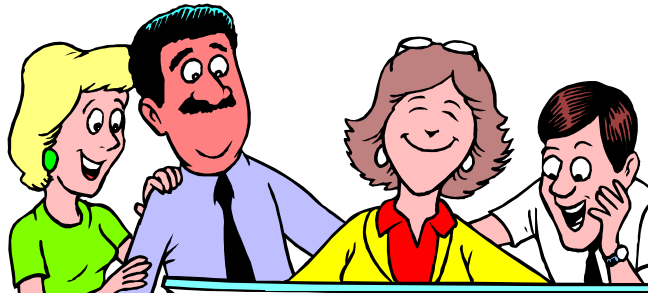
Nola. Given that there are no State Governments, the national government funds MS NZ directly. One of Nola's main tasks is to lobby the NZ Government for financial support to provide services and to fund MS research. The results to date have been disappointing, to quote Nola.

There are 19 MS support groups in New Zealand, far too many, and these consist of mostly outreach workers; all nurses and no counsellors. Some of these nurses reside in local hospitals and people with MS are expected to travel to see them, the rest do make home visits. The little government funding received by MS NZ is distributed to these 19 communities by Nola.

MS NZ is forty years old this year, is a member of the Neurological Alliance and is considering joining with MS Research Australia to fund MS research in NZ.

Robbie Costmeyer
CEO





Staff at the MS Society of the ACT

CEO

Robbie Costmeyer

Fundraising Manager

Peter Hurford

Fundraising Assistant

Simon Srbovski

Financial Accountant & 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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