

September 2009

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The 26th AGM of the MND Association of WA

Annual General Meetings are not always seen as very interesting occasions, and they are usually very formal proceedings perceived as a necessary requirement under the legislation that gives the organisation its legal entity. But AGMs are probably the most important meeting that an organisation holds for it is at such a general meeting that the members elect the people to govern and manage the association on their behalf. This year, following the trend, we barely made the quorum of 10% of the membership in attendance.

AGMs are also the forum for important announcements about the future directions of the association, and this year President Ross was able to advise the meeting of the very generous increase in funding from the Minister for Health, Dr Kim Hames. Our priorities for this new funding will be in extending MND Care Advisory services through additional information; filling gaps in current services, such as Counselling; building capacity in the sector Training Carers and Respite Workers, and additional respite services.

Professor Peter Silbert, State Director of Neurology, addressed the meeting, outlining the introduction of MND clinics at secondary hospitals based on the Model of Care developed by the MND Subcommittee of the Neurosciences and Senses Network of the Health Department. The model is as yet unfunded, but coordination of neurologists at several hospitals will be the base of the network of clinics. These changes will present some challenges for us, but will not diminish the role of the MND Care Advisors who walk along side our patient members, their cares and families.

Those who did attend found that the meeting and its associated activities were more interesting this year with the presentation of awards to individuals and organisations for their contributions to the association over the last five years. The details of the awardees can be found on page 3 of the newsletter.

Back to the business of the AGM, the election of the Board of Management. President Ross Whiteman was returned for his fourth term, along with the majority of the previous Board members: David Whiteman, Vice President; Julie Touchell as Secretary; Karen Smart, Treasurer; and Board members – Lois Peck, Marie Macdonald, Heather Joppek, Cheryl Coates and Dr Margherita Nicoletti, Karen Brown and Stephen Brown. Two vacancies still exist on the Board, which the Board may fill by appointment.

Sue Colyer

From the Executive Officer's Desk

Spring is the season of renewal at the trees show their new colours, the bulbs emerge from dormancy, and we look for the warmer days with hope. Some new things are happening in the MND spring garden – a new Board following the AGM on 12 September, new staff member, and our first “black tie” fundraiser, as well as the launch of the Equip MND campaign. More on each of those events later in this newsletter!

We welcomed Rose Gibbins as the Care Advisor who will support Marg Sealey's clients. Rose brings a wealth of experience and will make a great contribution to our Care Advisory team. And we congratulated Raquel Rodriguez who graduated of Sunday 6 September with her

Bachelor of Business majoring in Marketing and Public Relations. Raquel does a very professional job putting together our newsletter, promotional flyers and supporting our events.

This past week we obtained six “almost new” pressure care mattresses kindly donated by Rockingham Rotary. These new additions to our equipment pool will make sure that our clients have some comfort. In order to continue to upgrade and expand the pool of equipment, the Equip MND campaign commenced this month. The target? - \$25,000.00 to fund the maintenance and improvement of our equipment library. Watch the Equip thermometer rise from the Donations page on our web site!

This newsletter also gives you a link to the Federal Governments health reform report of June 2009 and the MND Australia response. It is worth looking at both sites. Another worthwhile community participation opportunity is the consultation forums being held by Disability Services Commission to explore respite needs, service models, community capacity and local issues to help inform the development of a new facility. For the next forum dates – see the back page.

Go gently
Sue Colyer

Contact Details

Centre for Neurological Support
 The Niche-Suite B
 11 Aberdare Rd, Nedlands 6009
 Phone: 9346 7355
 Fax: 9346 7332
 Email: admin@mndawa.asn.au
 Web page: www.mndawa.asn.au

Office Hours

9:00 am -4:30 pm Mon-Fri

After hours

Call 0439918052 to speak with a trained volunteer.

Emergency

If you have an urgent matter contact Sir Charles Gairdner Hospital on **9346 7391** or your nearest Emergency Department

Staff

Executive Officer.....Dr Sue Colyer
 Care Advisor.....Diana Menzie
 Care Advisor.....Samantha Whittle
 Care Advisor.....Rose Gibbins (Margaret Sealey)
 Office Administrator..... Soraya Kumail
 Accountant.....Ling Lee
 Project Administrator.....Raquel Rodriguez
 Fundraising and Events Manager.....Paul "Blocker" Wilson

Regional Contacts

Mrs Norma Freebury, ALBANY 9841 3276
 Mrs Sandra Marlow, GERALTON 9964 9034

Membership

MNDAWA is a member of MND Australia, with a delegate on the Board. It also has strong links with other MND Associations around Australia and internationally, and the MND Research Institute of Australia

Newsletter Panel

Editor.....Dr Sue Colyer
 Copy Editor.....Anita Berryman
 Sub Editor.....Raquel Rodriguez

Disclaimer: The articles provided in this newsletter sometimes contain personal opinions that may not reflect board policy. Research articles are selected from reliable sources, we do our best to ensure currency and accuracy.

Patrons

Mr. Jon Sanders, AO, OBE
 Mr. Keith Potger
 Mr. Ken Judge

Board of Management

President.....Mr Ross Whiteman
 Vice President.....Mr David Whiteman
 Treasurer.....Mrs Karen Smart
 Secretary.....Miss Julie Touchell
 Member.....Mr Stephen Brown
 Member.....Mrs Karen Brown
 Member.....Mrs Lois Peck
 Member.....Mrs Heather Joppek
 Member.....Dr Margherita Nicoletti
 Member.....Mrs Cheryl Coates
 Member.....Mrs Marie Macdonald
 Member.....vacant
 Member.....vacant

Honorary Positions

Mr Peter Murray..... Hon. Solicitor
 Mr Tony Silipo.....Hon. Accountant

Advisory Panel

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 Dr R. EdisRPH Shenton Park Campus Neurologist
 Prof F. Mastaglia.....SCG Hospital Neurologist
 Prof Nigel Laing.....Research
 Trevor Jones.....Assistive Technology
 Chris Kingsnorth.....Occupational Therapist
 Judy Griffiths.....Grief and Loss Counsellor
 Helen Sjardin-HowardSpeech Pathologist

Care Foundation Trustees

Karen Smart (Senior Trustee)
 Ross Whiteman
 Marie Macdonald
 Peter Murray
 Dean Finlay
 Bruce Ponting

NEWSLETTER DEADLINE

Items for the newsletter can be sent to
admin@mndawa.asn.au

Deadline is **Friday 25 September 2009**
 Send in stories, personal profiles, jokes or other items of interest.

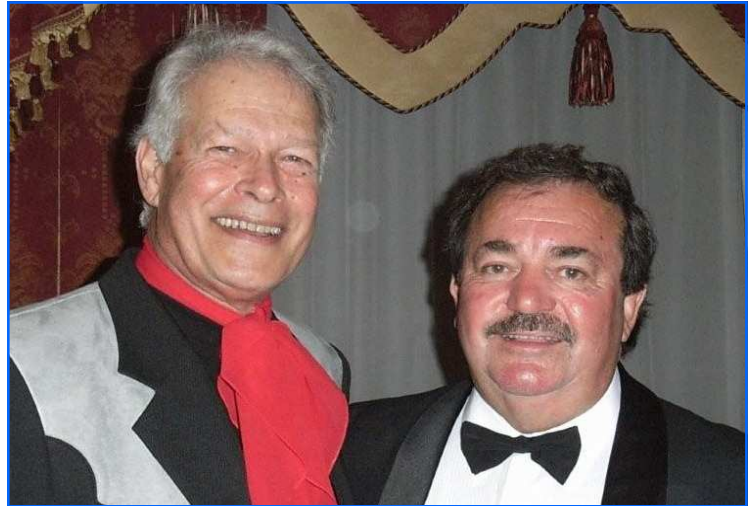
Visit our new look website
www.mndawa.asn.au

SEEKER ON THE SWAN

September 2009

We went seeking the Seeker and were not disappointed. Keith Potger was the main event at an evening of main events at our "black tie" awareness and fund raising event held on Saturday 5 September. More than 110 guests enjoyed tasty nibbles and good wine while signing up for a silent auction, buying raffle tickets for a 10 kilogram block of chocolate and then bidding with enthusiasm for a range of items that included dinner vouchers, boat cruises, pampering, golf days, and more chocolate. These items and many more were generously donated by the sponsors listed at the end of this article.

Then we gathered in the drawing room of Kevin and Petrice Judge's home overlooking the Swan River, for two sets of Keith Potger's special style of entertainment. We sang along and tapped our toes to the familiar songs of the Seekers, and enjoyed some of Keith's more recent songs. At the end of the evening Keith signed copies of his CD from which a donation will come to MNDAWA. Thank you Keith for a wonderful nostalgic trip with a touch of the future.



Keith Potger and President Ross Whiteman

An impromptu interview with John Sylvester (author of Underbelly) and Ross Stephenson (Morning radio host for 3AW) offered a humorous view of life of crime and writing about it.

Special thanks go to Kevin and Petrice Judge for opening their home for this special event, to Ken and Annette Judge, and Paul and Sally Wilson, and to all the sponsors and supporters. And well done to Paul for his first MND event.

Special thanks to sponsors of the Seeker on the Swan event...

Electrolux
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Kevin & Petrice Judge
Ken & Annette Judge
Paul & Sally Wilson
David & Gillian Helfgott
Michael Sutherland, MLA
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Whaleback Golf Course
Araluen Golf Resort
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Sue Colyer

~ 2009 AGM Awardees ~

President's Award

- Dr Sue Colyer

The Eleanor Mounsher Medal

- Heather Jopek

Certificates of Appreciation

- Mr Alex McKenzie, Executive Director, Royal Life Saving Society of Australia, Western Australia
- Mr Peter Leaversuch, Royal Life Saving Society of Australia, Western Australia
- Mr Allan Godfrey, HELLO Customer Contact Services
- Mount Lawley Golf Club

Silver Plaque (Donations \$5,000 - 10,000)

- AUSSI Stadium Snappers (Inc)
- Swan Valley Sporting Club
- The West Australian Golf Club
- Alanda Cafe

Gold Plaque (Donations \$10,000 - 49,000)

- Apache Energy Ltd
- Interhash Perth
- Jim Kidd
- Asics
- Maritime Union of Australia
- Australian Manufacturing Workers Union
- Ray White Real Estate
- Fremantle Public Golf Course
- The Rotary Club of Hillarys
- Banovich Hillman
- John Mounsher

Honour Board (Gold Plaque recipients and other supporters)

- Jim Kidd
- Asics
- Kambo's Investments Pty Ltd
- Swan Valley Sporting Club
- The West Australian Golf Club
- Maritime Union of Australia
- Australian Manufacturing Workers Union
- Ray White Real Estate
- Fremantle Public Golf Course
- The Rotary Club of Hillarys



2009 AGM Special guest speaker, State Director of Neurology, Professor Peter Silbert and MNDAWA President, Ross Whiteman.

Congratulations to all MNDAWA Supporters.

Spring is upon us and here's for hoping for some warmer days so we can get out into the sunshine.

We always welcome feedback from you and want to make these meetings enjoyable whilst informative.

Staffing changes

We have a change in staffing arrangements as Margaret Sealey takes four months off to concentrate on her University studies and finish her thesis. In her place, is Rose Gibbins who is very experienced. We are delighted to have her on board and hope you will all get an opportunity to say hello to her at some stage over the next few months. Rose has written a little piece on herself, featured below:

Hello to all the members of MNDAWA.

My name is Rose Gibbins and I would like to take this opportunity to introduce myself to you all. I have been lucky enough to be chosen to fill in the position for Margaret Sealey while she is on four months leave.



I am an Enrolled Nurse and recently have been working at the Fremantle Hospital since my arrival in Western Australia 10-11 months ago. Previously home was in South Australia where I spent time working with the neurological organisation, Julia Farr Services, caring for clients in the community and within a hospital environment. These were very enjoyable times, meeting and spending time with very interesting people. I am looking forward to meeting my clients here and having the time to get to know you all and vice versa.

*Take care and I will see you all at various times soon
Rose Gibbins*

Carers' Lunch

Another reminder that the Carers' lunch is now held on the fourth Tuesday of each month and NOT on the Monday. We are hoping to keep the meetings quite informal to allow carers time to chat amongst themselves for about half an hour, then have a group discussion or guest speaker for the next ½ hour to 45 minutes, and finish off with another informal session.

If anyone has a suggestion for a specific topic you'd like discussed in more detail, please let one of the Care Advisors know.

Handy Tips

Information

It is always very useful to keep records of your medical information together in one file. You should have a "patient file" which holds all of your doctor's reports; allied health reports (eg. Speech pathology, physiotherapy, occupational therapy, dietician, social work etc) and any other information relevant to your condition. It makes things much easier if you visit a new practitioner and they want to know who is involved with your care. We will be issuing a special folder shortly.

Neck support

If you suffer from a weak and perhaps sore neck, 'U' shaped or semi circular cushions made from polystyrene beads may be of assistance. They are very soft and supportive, and can be moulded around your head and neck. They are fairly widely available. Of course specialised neck collars are also available for those who have considerable neck muscle weakness.

Constipation

Constipation can be a problem when mobility function becomes less. One of our MND members was treated with Movicol medication whilst in hospice recently and recommends it.

Gentle Leg Exercise

An exerciser that you pedal, and has a motor assisting movement if necessary, has had benefit with some of our members with lower limb weakness. The MOTomed Viva is one such exerciser, I'm not sure if you are able to loan one through your physio, but perhaps a sporting store would have a similar type of machine that could be purchased. You can view this type of machine on the website: <http://www.rehab-ms.com>

If you have any questions relating to anything here, please don't hesitate to contact one of the Care Advisors at our office on 9346 7355.

Until next time, take care.

Samantha Whittle

Soup and Sweet Luncheon

Every July since 1994, a dedicated group of volunteers in Geraldton kindly donate their time and efforts to raise funds for MND through an annual Soup and Sweet Luncheon.

This year 135 people participated in the day's raffles, games and fun, helping raise a total of \$4,793.50 for MND. \$3,000 of which was donated to further developing MND research and the remainder used towards improving the quality of life for people living with MND.

Thank you to everyone who participated in this year's event with special thanks to Kath Millard and her group of volunteers who have been active in turning the annual event into a tradition. Your efforts and support are greatly appreciated by the MND community.



The volunteers taking a much deserved break after the days' events.

MND DIARY for SEPTEMBER to NOVEMBER

September 2009

Date	Event	Time	Venue
September			
Tues 22 Sept	Carers Group	11:30am - 1pm	The Niche – Volunteers Room
Wed 23 Sept	Greyhounds	6:30pm for 7pm start	Checkers Restaurant at Greyhounds Contact Heather Joppek on Ph: 9314 3863
October			
Thurs 1 Oct	Craft Day	10am - 2pm	The Niche
Sun 18 Oct	Hope and Remembrance Day	1pm - 4pm	Carilley Estate Vineyard Restaurant
Sat 24 Oct	Pampering Day	11am - 3pm	The Niche – Conference Room
Tues 27 Oct	Carers Group	11:30am - 1pm	The Niche – Conference Room
Thurs 29 Oct	Past Carers Group	2pm	Eddy Froend 19 Bitton St. Hamilton Hill Ph: 9337 2295
November			
Thurs 5 Nov	Craft Day	10am - 2pm	The Niche
Tues 24 Nov	Carers Group	11:30am - 1pm	The Niche – Conference Room
Thurs 26 Nov	Past Carers Group	2pm	Heather Joppek 11 Masefield Ave. North Lake Ph: 9314 3863
Sun 29 Nov	Family Christmas Sausage Sizzle	11am – 3pm	Sir James Mitchell Park Clydesdale Park - South Perth Douglas Ave, just off Coode St

Keep us in touch with your communication needs.

Don't forget to let us know if you have changed your address, email or phone details.

Complete this form and return to MNDAWA :
How would you like to receive the Newsletter?

Via Email (Please provide your address clearly)

By post

Changed address?

Name: _____

New Address: _____

_____ Post-code _____

Phone _____

Mobile _____

Complete, cut out and send this form to:

**MNDAWA - The Niche,
Suite B/11 Aberdare Rd,
Nedlands WA 6009**

Or email your response to:
admin@mndawa.asn.au

 **Hope and Remembrance Day**

Join the WA MND community for a celebration of life, hope and to remember loved ones.

**Sunday 18 October 2009
1pm - 4pm
Carilley Estate
Vineyard Restaurant**

Lot 23 Hyem Road, Herne Hill
WA 6056

RSVP by Monday 12 October
2009 on ph: 9346 7355 or via
email: admin@mndawa.asn.au

Interested in becoming a member?

Stay up to date with upcoming events, research breakthroughs and other information within the MND community by becoming a member!

Membership categories include:









	Annual Fee
Ordinary member	
- supporter	\$20
Patient member	
- diagnosed with MND	\$10
Care member	
- carer of person diagnosed with MND	\$10
Associate member	
- students, or non-WA residents	\$10
Corporate member	\$100

If you or anyone you may know are interested in becoming MNDAWA members, please contact us on (08) 9346 7355 where we will assist you through the process.

Alternatively, you may download a PDF version of the membership form online at www.mndawa.asn.au fill it in and post it to the office.

Your support is greatly appreciated.

Christmas Card Order Form 2009

Description	Price per card	Quantity	Total Price
 <p>1. Three Kings - Kings showing their respect for the season. Inside: Joy at Christmas and Happiness in the New Year.</p>	\$0.80		
 <p>2. Dove and Stars - Spreading peace. Inside: Christmas Greetings and Best Wishes for the New Year.</p>	\$0.70		
 <p>3. Sparkling Stars - Getting into the festive mood. Inside: May the joy and peace of Christmas be with you today and always.</p>	\$0.90		
 <p>4. Gum Leaf Greetings - An Aussie Christmas. Inside: Warmest greetings of the Season and every good wish for the coming Year.</p>	\$0.90		
 <p>5. Festive Puppies - A warm card that reflects the celebration of Christmas. Inside: Bringing you all the Season's best wishes.</p>	\$0.80		
 <p>6. Gum Blossom Greetings - Pink gum blossom and gold foil greetings. Inside: Warmest greetings of the season and every good wish for the coming year.</p>	\$0.90		
 <p>7. From All of Us - Having a bountiful Christmas. Inside: Christmas Greetings and Best Wishes for the New year.</p>	\$1.00		
 <p>8. Tree Parade - A bit of colour and glitter. Inside: A wish for Peace and Happiness at this Christmas Season and throughout the New Year.</p>	\$0.90		
9. Mixed Pack of 10 Cards		\$5.00 per Pack	
<p>NB: Minimum purchase of 5 cards per order</p> <p>Name.....</p> <p>Address.....</p> <p>.....</p> <p>Please return your order along with payment to MND Association of WA Suite B/11 Aberdare Rd Nedlands 6009</p>		TOTAL ORDER	
		<p>Postage: Orders under \$5 add \$3.50 Orders \$5 to \$25 add \$5.70 Orders over \$25 add \$7.00</p>	
		TOTAL BALANCE DUE	

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Debra Gray
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Ministry of Sport and Recreation
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VG & MJ Ridge
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PA Hopps
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Tania Herning

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Bethel Flavel
- Neville Pratt
Joe Donald
- Margaret Donald
Pam Blake
- Lorina Maley
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- Department of Innovation
Vivienne Mickfe
- Lois & Graham Peck

September 2009

Cornflowers

Margaret Rogers
Bunnings Melville
Alanda Caffè

Donor Appeal

CS & LA Rocke
Annemarie McKenzie
Joy Gunthrie

Change4Change

N Van Der Snoek

A special thanks to Ron and Jenny Hiller for their wonderful artwork gift. It is greatly appreciated and loved by everyone in the office.

MND Australia's Submission to National Health and Hospital Reform Commission: *A Healthier Future for all Australians - Final Report June 2009*

How would the proposed health reforms affect MND care?

This is a very much abridged version of the response from MND Australia that informs the MND community of the key elements of the report, what these reforms mean for people living with MND, and MND Australia's work on your behalf to help effect better care and support for people living with MND in Australia.

Prime Minister Rudd and Minister Roxon released the National Health and Hospitals Reform Commission final report in July 2009. The government is yet to make any major decisions about the future control of the health system, but has committed to consult with the health care community over the next six to eight months.

In its final report, ***A Healthier Future for All Australians***, the Reform Commission recognised that the case for reform was compelling and that whilst the Australian health care system has many strengths, it is a system under growing pressure. The reform agenda urges action to:

- Tackle the major access and equity issues that affect people now;
- Redesign our health system to meet emerging challenges; and
- Create an agile, responsive and self-improving health system for future generations.

The final report includes 123 recommendations that comprise a long-term reform plan, designed to achieve better health for all Australians and improve the performance of the health system. Some of these recommendations, identified below, have the potential to impact positively on people living with MND and their families, and many reflect elements of the submissions MND Australia made to the commission. The recommendations are not reproduced here, but may be found from the web addresses at the end of this article.

MND Australia acknowledges that many aspects of the report if implemented have the potential to improve outcomes for people living with MND and their families and will continue to monitor with interest the reform process. Of particular interest are the major recommendations for reform that focus on:

- Timely access to quality care in public hospitals
- Delivering better outcomes for people in rural and remote communities
- Primary Healthcare as the cornerstone of our future health system

- A 'health care home' for people with chronic and complex needs
- Improving access to palliative care
- Supporting carers
- Valuing and harnessing the expertise of our workforce
- Enabling an e-health environment
- Fostering quality collaborative care through funding
- Funding to better respond to people's care needs over time
- Enabling innovation and research system-wide

There are some aspects of the report that raise concerns for MND Australia. The report proposes that the Commonwealth Government takes on responsibility for the policy and funding of a range of services including aged care services. There is the potential for the needs of people living with MND to continue to be overlooked in this process. MND Australia will continue to advocate for services based on the needs of the individual with MND and their family.

Some of the recommendations that have potential to impact positively on MND care:

Taking responsibility:

Recommendations 12, 13, and 14.

Connecting Care:

Recommendations 18, 19, and 20.

Ensuring timely access and safe care in hospitals

Recommendation 31.

Restoring people to better health and independent living

Recommendations 38, 40, and 41.

Increasing choice in aged care

Recommendations 49, 50, 51, and 52.

Caring for people at the end of life

Recommendations 54, 55, 56, and 57.

Delivering better health outcomes for remote and rural communities

Recommendations 65, 66, and 67.

The full report is available at the Commission's website: <http://www.nhhrc.org.au/internet/nhhrc/publishing.nsf/Content/nhhrc-report>

MND Australia submissions to the NHHRC available at the MND Australia website:

<http://www.mndaust.asn.au/submissions/>

Carol Birks
National Executive Director
MND Australia

Carers

The Disability Services Commission is interested in hearing from carers about ideas to help inform and design the best respite facilities for adults with disabilities. Your help will enable a range of different support needs to be covered in the State Governments' plans to establish five out-of-home respite facilities.

Community forums will be held to explore respite needs, service models, community capacity and local issues to help inform the development of a new facility.

The next forums will be held:

Tuesday 22 September 2009

7:00-8:30pm at the Joondalup Disability Services Commission Office – Conference Room
8 Davidson Tce, JOONDALUP 6027

Thursday 24 September 2009

9:30-11:00am at the Joondalup Disability Services Commission Office – Conference Room
8 Davidson Tce, JOONDALUP 6027

If you have any queries, please contact Catherine Doherty, Senior Policy Officer – on (08) 9426 9222 or catherine.doherty@dsc.wa.gov.au

Alternatively, you may wish to voice your ideas via email on respiteconsultations@dsc.wa.gov.au

Pampering Day



Saturday 24 October 2009

11:30am - 3:00pm

The Niche - Conference Room

Join us for a day of complete pampering.

Services will include: reflexology, reiki, healing touch and pranic healing, feet and hand massages.

RSVP on Ph:(08) 9346 7355 by 16 October 2009.

Past Carers

Volunteers still required for research study

Outcomes of this study may reveal **IMPROVEMENTS** to the **SUPPORT** and **BEREAVEMENT SERVICES** available, and may also highlight other MND support services that may require further development.

Past carers who have not yet participated in this study should consider telling their story of their MND journey with their loved one in a supervised research study**. Your participation plays an important role in this process.

If you are interested, or have any questions, please contact

Sianne Connors
Curtin University Masters student,
ph: 0437 208 139
email: sianne.connors@postgrad.curtin.edu.au

** This study is approved by the Curtin University Human Research Ethics Committee.



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2009 - 2010

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