

DECEMBER 2008

MND Research Grants 2009	1
News from Executive Director	2
Client Support News	3
Fundraising/Supporter News	4-5
Your Stories	6
Merchandise / Diary Dates	7
March of Faces Banner	7

FOUNDER

[Terry Maroz](#)

PATRON

[Jeremy Cordeaux AM](#)

MNDASA BOARD:

CHAIRMAN

[Stephen Warren](#)

SECRETARY

[Adam Kennedy](#)

TREASURER

[Sharon Perkins](#)

MEMBERS

[Dr Greg Crawford](#)

[Julia Greig](#)

[Marion King](#)

[Peter Whitehouse](#)

[Grant Wooller](#)

MNDASA STAFF

EXECUTIVE DIRECTOR

[Peter Whitehouse](#)

CLIENT SUPPORT COORDINATOR

[John Gilligan](#)

ADMINISTRATION ASSISTANT

[Ricki Higham](#)

ADDRESS

23A King William Road

PO Box 359 Unley SA 5061

Phone 8357 0245

Fax 8357 0265

Email: admin@mndasa.com.au

Internet: www.mndasa.com.au

ABN 87 026 807 478

MND RESEARCH INSTITUTE OF AUSTRALIA RESEARCH GRANTS 2009

It is very pleasing to report the MND Research Institute has awarded \$550,000 for research projects commencing in 2009. This follows on from the \$705,000 awarded for research projects that commenced in 2008.

Details of the 2009 Grants are shown in the enclosed MND Research Institute newsletter.

Dr Julie Atkin Motor Neuron Disease Research Team, Howard Florey Institute, University of Melbourne.

New therapeutic approaches for MND based on ER stress inhibition

Peter Stearne Grant for Familial MND Research

Dr Ian Blair ANZAC Research Institute, NSW

Identifying novel genetic loci for familial motor neuron disease

MND Victoria Research Grant

Dr Fiona Fisher Clinical Neuropsychologist, Calvary Health Care Bethlehem, VIC

Cognitive and Behavioural changes in MND: exploring the impact on caregivers.

Mick Rodger Benalla MND Research Grant

Dr Anna King Menzies Research Institute, University of Tasmania

The role of distal axonal degeneration in ALS

Charles & Shirley Graham Family MND Research Grant

Dr Marina Kennerson ANZAC Research Institute, NSW

Finding genes causing familial motor neuron degeneration

Henry H Roth Charitable Foundation MND Research Grant

Professor Nigel Laing Western Australian Institute of Medical Research (WAIMR)

Genome-wide mapping of modifying loci in Familial ALS

Zo-eè MND Research Grant

Dr Louisa Ng Rehabilitation Physician, Royal Melbourne Hospital, VIC

Disability in Motor Neurone Disease

Mick Rodger Benalla MND Research Grant

Dr Robyn Wallace Queensland Brain Institute, University of Queensland

Identifying biomarkers for MND using flow cytometry

Bill Gole MND Postdoctoral MND Research Fellowship (2009 - 2011)

Dr Justin Yerbury Centre for Medical Biosciences, University of Wollongong

Probing molecular mechanisms of microglial and astrocyte activation in ALS

WE ARE MOVING!

The Motor Neurone Disease Association of SA Inc will be moving to new premises in late January to **302 South Road, Hilton, SA 5033**. Our new phone number and other details are not yet available. As soon as we know we will post details on our website and advise clients and friends of the Association.

The MND Association incurred an operating loss for a second year and this again highlights the challenges for the Association that it must have regular and recurrent sources of income to ensure its client services are maintained at existing levels.

While the level of donations and fundraising income increased in the past year, the Association was not as successful in obtaining grants from philanthropic trusts and other organisations as was the case in previous years. During the year, the Chairman and I met on three occasions with the State Government's Office for Disability and Client Services to put our case for recurrent funding to support our client services. While the Office acknowledged and appreciated the valuable contribution made by the Association, we were subsequently advised that funding would not be provided. This was the third occasion our funding request has been declined. Given the well known level of the inadequate funding to the disability and health sector, the 'no' to our request was not surprising. The Association will continue to pursue the State Government for funding support.

Progress was made with some elements of the Strategic Plan, but with a number of strategies contingent upon a required level of income, a number of strategies could not be progressed. The Committee of Management took specific action aimed at improving the financial position and is currently redeveloping the Strategic Plan with a focus on achieving relevant and achievable objectives.

On the national scene, MND Australia continues to develop its profile and is evolving as a national body representing the interests of all MND persons. Changes to the MND Australia Constitution allows each State Association be represented by its Chairman. It also has provision to invite high profile or eminent persons to join the MNDA Board who are considered can make a significant contribution to the advancement of MND Australia. Both MND Australia and the MND Research Institute have agreed to merge into a single national entity that will result in an improved and much stronger entity representing the needs of the MND community.

With Christmas and the New Year almost with us, it is time of reflection and I trust will be enjoyed with family and friends.

[Peter Whitehouse](#)
Executive Director



MNDASA

Christmas Closure Dates

Our office will be closed from Monday, 22 December and re-open on Monday, 5 January 2009.

In you need to speak with John Gilligan during this time, please call him on 0422 182 896.

Motor Neurone Disease Clue Found

Scientists have identified a molecule which could be key to understanding the cause of Motor Neurone Disease (MND) and other neurodegenerative disorders.

The Proceedings of the National Academy of Sciences study raises the hope of new treatments being developed. The London-based team showed the molecule, Wnt3, plays a key role in establishing connections between nerve cells and the muscles they control. These connections become progressively weaker in MND patients.

Without properly-formed connections - or synapses - the muscle cannot receive the nerve signal that tells it to contract. This results in the muscle weakness that is typical of MND. However, scientists have not been clear how synapses are formed in normal circumstances and this has made it very difficult to pin down what goes wrong in MND.

The researchers, from University College London and King's College London, identified Wnt3 as key to the process. It assists a second molecule, called Agrin, which co-ordinates construction of the connection - or synapse.

Lead researcher Professor Patricia Salinas (University College London) said: *"The work we are publishing today puts an important piece of the puzzle in place and offers up a new possibility for developing drugs to treat MND and other neurodegenerative diseases. If we can build up a thorough picture to show how synapses are normally formed between nerves and muscles we can start to look for any elements that aren't working properly in people with MND. This might also lead to strategies for nerve repair after an injury."*

Animal studies

The team of researchers looked at the function of Wnt signals in chickens, mice and in cells. In all three cases, it was shown to enhance the effectiveness of Agrin.

Professor Salinas added: *"Chickens that don't have the Wnt signal in their developing wings have all of the muscle tissue that we would expect to see, but they don't make strong connections between nerves and muscles. So we know that Wnt is definitely affecting synapse formation rather than anything else to do with muscles. Now that we understand the role Wnt plays we can begin to explore any role it plays in MND and whether it could be a good target for treating this type of neurodegenerative disease."*

Dr Belinda Cupid, of the UK MND Association, said: *"We know from recent research that signs of motor neurone damage, on a cellular level, in models of MND occur very much earlier than the symptoms appear, so any new knowledge of how healthy motor neurones and muscles interact will give us new clues about what might be going wrong in those people affected by this cruel disease."*

CLIENT SUPPORT NEWS

Hi Everyone

Needless to say this is my last column for the year so may I start by wishing you all a very *Merry Xmas* and a *Happy New Year*. I am always mindful of the irony of this wish in the context of those stricken with Motor Neurone Disease but I sincerely hope you are able to make 'merry' and to be 'happy'.

No one particular topic of interest for this last column, just a collection of items by way of wrapping up the year, and focusing on some initiatives for next year.

By now you will have realized that the phone survey which was scheduled to occur earlier this month didn't. Unfortunately, our student who was to conduct the survey was unwell and consequently unable to participate. A copy of the survey will be mailed to you shortly. **I hope you have the opportunity (and inclination) to spend some time on completing and returning the survey.** Apart from identifying 'gaps' in services provided by various agencies/organizations, we at the Association hope the information you provide will be the catalyst for the MNDA to apprise itself of our role moving into 2009.

Since joining the Association I have had the opportunity to speak / meet with many of you and it is my intention to maintain this relationship as we enter a new year. I am however aware that I have not had contact with many currently reading this newsletter. There are a number of reasons why this is the case, not the least of which is what purpose I could serve in contacting you at this time. That said I trust that if you want, need or would like to have contact with me, you will phone. Having worked as a nurse for over 36 years I have come to the realisation, particularly in the context of working amongst people with life-limiting conditions that sometimes the most therapeutic thing I can do is just be there to listen to someone. I must confess however to being a better talker than listener (it's the Irish in me, I can't shut up) but I am getting better. I once heard a colleague of mine say to a client, *"I can't take you out of the darkness, but I can sit in it with you."* I have come to appreciate the magnitude of that statement.

One topic that has arisen at various times is the **Carer's Meeting**. We have had a couple of unsuccessful attempts to organize various functions but we remain optimistic of re-establishing this important activity in 2009. You will note its inclusion on the survey.

On a completely different issue a couple of our members have recently begun wearing the '**Headmaster Collar**'. This collar is designed to provide head support and control and has received excellent endorsement for individuals with MND in comparative reviews. Please feel free to give me a call if you require further information about this collar.

And finally we have 8 copies of the book *"Good Looking, Easy Swallowing"* by Janet Martin and Jane Backhouse available for loan. This is a great book, designed as a resource for caterers and caregivers of people with swallowing difficulties (dysphagia). It contains some valuable information about the aforementioned problem and an abundance of mouth watering recipes. So if you are struggling to come up with some variety in your diet please feel free to give us a call.



Well that's about it from me, catch you in the New Year

Warm regards
John Gilligan
Client Support Coordinator

Mobile Support Rehabilitation Unit

A rehabilitation group for people with progressive neurological condition. It will target:

- ☺ Sitting and standing balance
- ☺ Transfers
- ☺ Gait retraining
- ☺ Falls prevention
- ☺ Fine motor skills
- ☺ Reach and grasp

When: Mondays : 10.30 - 2.30 pm
2 February until 6 April

Where: Malvern Uniting Church, 44 Marlborough Street, Malvern

Cost: \$6 non-members (\$72 for term)
\$4 members (\$48 for term)

RSVP on 8360 0800 by 20th January 2009

Chair Based Exercise Class

For people with progressive neurological conditions.

The program content will include: upper body strength and flexibility, general fitness, fine motor coordination *eg grasping objects*, head and trunk control and core strength.

A physiotherapist from the MS Society will be organizing the exercise plan, with students from TAFE SA and Uni SA assisting.

When: Tuesdays : 10.30 - 11.45 am
20 January to 7 April

Where: Reynella Neighbourhood Centre

Cost: \$6 non-members (\$72 for term)
\$4 members (\$48 for term)

Please phone Kirsti on 8360 0800 by 13 January.



FUNDRAISING & SUPPORTER NEWS

Friends in the Barossa

Pfeiffer Festival

On October long weekend each year, the Pfeiffer family, the owners of Whistler Wines celebrate their name and heritage on the long weekend each year.

The family are marvellous supporters of the MND Association and they invited Barossa Valley MND fundraising stalwarts, Marjorie Coats and Tia Schubert to organise a Gourmet BBQ and raffle with proceeds to the MND Association.

The food and other items for the gourmet BBQ were donated by [Mark Viney Primo Smallgoods](#) Gawler, [Tanunda Supa Barn](#), [Trevor & Marilyn Giles Northland Packing](#), [Maggie and Colin Beer](#), [Apex Bakery Tanunda](#) and [Wilma McLean of McLean's Farm Wines](#) while [Whistler Wines](#) donated a GSM magnum for the raffle.

'JazzBird,' Wendy McPhee entertained the appreciative crowd and donated the proceeds of sales on the day of her CD to the MND Association.

The Festival was a most enjoyable and successful day raising almost \$2,000 for the MND Association.

The Association is indebted to the wonderful support its receives from the *'Friends in the Barossa.'*



Peter Whitehouse, Rae Harry, Tia Schubert, Des Wyatt and Marjorie Coats preparing the gourmet BBQ



"Jazzbird," Wendy McPhee entertains the crowd



A competitor tries his luck in the "Whistling Competition."



Peter Whitehouse (MND CEO) with Barossa Raffle winner Allen Wait (middle) and Neale Stephens



Rae Harry, Tia Schubert, Maggie & Colin Beer and Marjorie Coats

Walk to D-Feet MND 2009

Sunday, 26th April 2009

Adelaide Sailing Club

Barcoo Road, West Beach

Walk / Run 4 km with an optional 1.8 km extension to Henley Life Saving Club.

Keep this date free. Registration / sponsorship forms will be available early 2009.



Superannuation

The Australian Tax Office website www.ato.gov.au provides information about early access to superannuation for people with terminal medical conditions.

Information about the legislation allowing tax-free lump sum payments and answers to questions about accessing super tax-free can be found on:

www.ato.gov.au/distributor.asp?doc=/content/Content/00158639.htm

Thank you

Special thanks to everyone supporting the work of Motor Neurone Disease Association of SA Inc by memorial donations in lieu of flowers when a loved one passes away.

The donations received from families, friends, and colleagues are promptly acknowledged.



This quarter we have received generous donations from Clubs, Local Government Councils, Government Departments, clients, carers, families and friends, through memorials and general donations, staff collections, fun activities and celebrations.

☺ We would like to thank Kylie Harding from Café Palazzo at Norwood for allowing Elizabeth Wheldrake to use the Café on the 31 October to do Tarot readings. Elizabeth raised \$300 which she donated to our Association.

Awareness Week

3 - 9 May 2009

Can you help?

MND Awareness Week will be held from 3 – 9 May 2009. We plan to make this week *"bigger and better"* in 2009!! Community Access sites have been booked at the following shopping centres to display MND information and merchandise.

Friday, 1 May	Burnside Village
Wednesday, 6 May	Tea Tree Plaza
Friday 8 May	West Lakes Shopping Centre

A staff member or Planning Committee Member will be on site for the whole day. Two people are required at all times. **If you have an hour or two to spare and would like to assist at any of these venues**, please phone our office on 8357 0245 **or complete the slip enclosed and return in the Reply Paid envelope.**

Collecting / selling merchandise

We are hoping to target as many people as we can during this week. Can you assist us?

Do you know of any friends or businesses who would be interested in having MND collection tins / merchandise at their workplace? **If you do**, please contact our office on 8357 0245 or complete the slip enclosed and return in the Reply Paid envelope to register your interest.

Memorial Service

Date and time for our Memorial Service will be finalized in February. Information will appear in our March newsletter.

Lions Xmas Raffle

Thank you to everyone who sold / purchased tickets this year. Prizes will be drawn on Wednesday, 17 December at the Marion Hotel. Results will be published in The Advertiser on Friday 19 December. Good luck!



Australian  Central

Next year MNDASA will be participating in the 2009 Australian Central Community Lottery.

Tickets will sell for \$2.00 each and the full amount from each MNDASA ticket sold will be donated to MNDASA. Prizes are still being finalised and it appears that the organisers are aiming to have 150 prizes on offer with a value of \$220,000.

We expect that tickets will be available in February 2009 and we will be in contact with our members and supporters early in the New Year to seek out your assistance with MNDASA ticket sales.

During 2009, we aim to sell 200 Lottery tickets which will in turn raise \$4000.00 for the Association.



YOUR STORIES

Back in 2004 my good friend Tia Schubert showed me a story in the MND newsletter written by her niece Michele Inglis of Whyalla outlining her struggle with MND and its effect on her family. I was so moved by her story and suggested to Tia that we could perhaps raise a little money towards finding a cure.

Whilst I had always known of Motor Neurone Disease and the well known sufferers of this illness, Michele's story changed me totally and so I became a fundraiser for MND for South Australia. At this point I did not know Michele or many of her large family, but now feel privileged to call them good friends.

Michele is without a doubt one of the world's special people, she makes you feel good just being with her. Always smiling, even on her poorer days and sets herself goals to keep going. One of these was to reach her 40th birthday in September. 120 people came to her party on the Saturday where Ben, her 12 year old son wrote and delivered a speech. One of his memorable comments was, *"When things get rough, Mum gets tough!"* Her immediate family celebrated with lunch on the day.

Michele is supported by Andrew her husband. Her delightful sons Ben and Jared, her parents Ann and Renzo and her large extended family.

Michele has been living with MND for 8 years. Sadly I have now met a number of people affected by MND including the inspirational Neale Stephens, but Michele remains my hero and is responsible for my commitment in raising money for Motor Neurone Disease research and hopefully a cure.

Together we can make a difference.....

Marjorie Coats

Angaston

Fundraiser and supporter



Michele with her husband Andrew and sons Jared (left) and Ben at her 40th Birthday celebration

MERCHANDISE

Merchandise

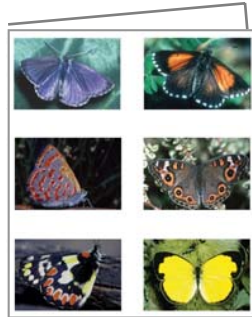


- MND BALLPOINT PENS \$2
- WRISTBANDS \$2
- GREETING CARDS (5 per pack) \$5
- LAPEL PINS/BADGES \$3
- SILK BROOCHES \$2
- MND SOCKS \$6

Greeting cards come in three different designs.

Pictured is a popular design displaying 'A selection of SA Butterflies', photographed by Lindsay Hunt.

A pack of 5 cards and envelopes costs only \$5.00



These comfortable padded socks come in small or large sizes and at only **\$6.00** a pair they're a fantastic buy!



DIARY DATES

MNDASA moving to Hilton

☺ *Late January 2009*



Xmas Closure

☺ Our office will be closed from Monday 22 December and will open again on Monday 5 January. If you need to speak to John Gilligan during this time please contact him on 0422 182 896.

Walk to D-Feet MND 2009

☺ *Sunday, 26th April* - Planning Committee meeting regularly. Information, Registration / sponsorship forms available early 2009. Possibility of Regional Walk being held in Mt Gambier later in the year.

Awareness Week 2009

☺ *Monday, 3rd May - Friday, 9th May*

MARCH OF FACES BANNER

The March of Faces banner features a photographic display of people with MND.

MNDASA has produced two banners and we aim to produce a third banner as soon as we have 20 new faces. *At the present time we have seven new faces.*

If you have MND you can be included in the banner once you have completed a permission form and submitted a photograph of yourself. You are welcome to include family or caregivers in the photo if you wish.

Family members are also able to submit a photograph in remembrance of a person who has died from MND. If you would like further information, please contact us on (08) 8357 0245 or email us at: admin@mndasa.com.au

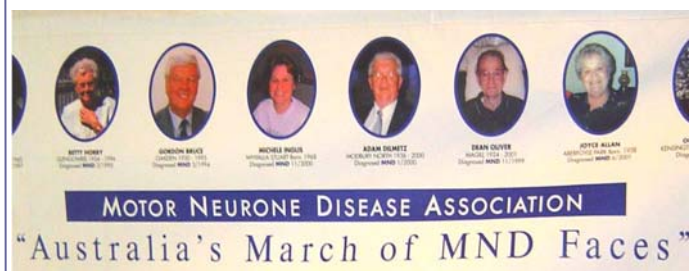
Support from United Petroleum for MND Research

United Petroleum will give one cent per litre to the MND Research Institute every time you fill up your car at a United service station and present your United - MND Research Institute community card. The card is FREE.

To receive a card, please contact either Janet Nash at the MND Research Institute of Australia on 02 8877 0990 or email info@mndresearch.asn.au to ask for a Research Institute community card to be sent to you, or phone the MND office on 8357 0245.

United Outlets: South Australia

ADELAIDE AIRPORT	Sir Richard William Avenue, ADELAIDE AIRPORT
BERRI	Cnr Sturt Highway & Zante Street, BERRI
BLAIR ATHOL	369 Prospect Road, BLAIR ATHOL
CROYDON PARK	328-330 Torrens Road, CROYDON PARK
MURRAY BRIDGE	155 Adelaide Street, MURRAY BRIDGE
PORT WAKEFIELD	6 SNOWTOWN ROAD, PORT WAKEFIELD
REMARK	220 Renmark Avenue, REMARK
RICHMOND WEST	128 Marion Road, WEST RICHMOND
SALISBURY	1-3 Salisbury Road, SALISBURY
SEATON	169-171 Tapleys Hill Road, SEATON
STRATHALBYN	18 South Terrace, STRATHALBYN
TRURO	52-56 Moorundie Street, TRURO



We welcome articles, stories, poems etc from all of our MNDASA members and friends. If you would like to send us an item for the next MND Newsletter please send us an email at: admin@mndasa.com.au or post your information to PO Box 359, Unley, 5061.

Do you have an item for sale that may be of benefit to MND clients? If you would like to advertise an item in our next Newsletter, please send us an email at: admin@mndasa.com.au ... or you can post your information to PO Box 359, Unley, SA 5061.



If undelivered, please return to:

The Motor Neurone Disease
Association of SA Inc

PO Box 359

Unley SA 5061

MND Newsletter

Print Post Approved

PP 544876/00014



PRINT
POST

PP 544876/00014

POSTAGE
PAID
AUSTRALIA

We are moving!

The Motor Neurone Disease Association of SA Inc will be moving to other premises in late January to

302 South Road, Hilton, SA 5033

Our new phone number and other details are not yet available. As soon as we know we will post details on our website and advise everyone associated with the Association.