

MND NEWS



July – August 2009

Diary Dates

- Monday 10 August 2009
Information Night
Canterbury 7pm - 9pm
- Sunday 30 August 2009
Outer Eastern Sunday Lunch
- Saturday 5 September 2009
Sausage Sizzle, Hawthorn
- Monday 26 October 2009
Annual General Meeting
See notice page 4
- 8-10 December 2009
International Symposium on
ALS/MND, Berlin, Germany

Motor neurone disease (MND) is a disease in which the nerves controlling the voluntary muscles gradually fail, causing muscle weakness, wasting and paralysis.

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From the desk of the CEO

There are a number of items for this newsletter that are more fully presented either in flyers or in the newsletter text. I will give my take on them, and whet your appetite for more.

Corks – congratulations to all of our cork collectors. In the financial year ended 30 June, we have received over \$25,000 from collecting, selling and recycling corks. This is just less than 17 tonnes of cork, or 3,978,000 corks. Thank you to all our commercial suppliers and to our individual collectors, aggregators, deliverers and sorters who make this possible.

zo-eè Motor On – 2010 is in planning, after a very successful 2009 event.

zo-eè - BackSpin Trivia Night – Another zo-eè event is being planned for 20 August, with a trivia night focusing on music trivia – old school to new school! And what of Michael Jackson? Sounds like it will be a great event, and another fundraiser for research into MND. Who did say, “be there, or be square”?

The one after the Inaugural Ball – a fantastic night was enjoyed at Powerhouse and over \$47,000 raised for investment in research. Nearly 300 guests enjoyed competitive auctions, good food and wine, and wonderful entertainment to come together in support of research for MND. Plans for the next “one after” are in the wind ...

End of Year – at this time, much of Peter's and my time is consumed by end of year activities. We have to make sure that the financial and service reporting is transparent, and to give members, donors, clients, funders and supporters a very clear view of the Association's successes, and our weaknesses. This year, despite the wider impact of the global financial crisis, and of more local community tragedies like the bushfires, the Association has traded well. Financially, we have exceeded our budget income significantly and maintained our budget expenditure. Details will not be available until the audit is completed in late July, and will be published in the Annual Review and the Annual Financial Report. However, I can say that we enter 2009/10 in a strong financial position. We will be able to address the Association's objectives, and deliver and promote the best possible care and support for people living with MND.

Care Foundation – the MND Care Foundation continues to grow and to make significant contributions to the work of MND Victoria. The current balance is just short of \$1.5 million. All funds are invested and generate income that is applied to MND Victoria support services for people living with MND. A new entity within the Care Foundation has been created – the Susie Harris Foundation - which honours the memory of Susie and is a focus for her family and friends to continue to raise funds for the Care Foundation, and the fight against motor neurone disease.

(Continued on page 4 ...)

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Fax: (03) 9830 2228
Email: info@mnd.asn.au
Internet: www.mnd.asn.au

*Working towards a world without
motor neurone disease*

PATRONS

Lou Richards
Mr Justice John Winneke AM QC

STATE COUNCIL 2007-2008

President - David Ali
Vice-President - Mavis Gallienne AO
Hon. Treasurer - Hugh Parkes

Glenys Barry
Betty Ryan
Penny Taylor
Christopher Beeny
David Lamperd
Graham Lang
Andrew Marshall

STAFF

Chief Executive Officer

Rodney Harris OAM

Office Manager

Peter Allen

Manager of Fundraising

Indira Kennedy

Manager Family Support Services

Julie McConnell

Coordinator Family Support Services

Janette McDonald

Regional Advisors

Ruth McEvoy	North & Outer East Metro
Sally Boal	Barwon Region & Western Metro
Lesley Burcher	Inner East & Inner South Metro
Eric Kelly	Hume, Grampians, Loddon and Barwon South West
Jenny Waites	Outer Southern Metro and Gippsland

Equipment Service

David Harkin
Noel Gardiner

Coordinator of Volunteers

Prue Gilligan

Coordinator Information & Research

Inez van Polanen

Information & Development

Rebecca May

METROPOLITAN SUPPORT GROUPS

OUTER EASTERN METRO SUPPORT GROUP

Bayswater Community Youth Centre,
Corner Station St & Pine Rd, Bayswater.
Meet second Thursday of the month at 11 am.
Contact: Mrs Marian Lowe, 9762 9429.

WESTERN METRO SUPPORT GROUP

MS Society, 398 Barkly St Footscray.
Last Monday of the month at 12.30pm.
Contact: Mrs Christine Robson 9379 7715.

RURAL SUPPORT GROUPS

BARWON REGIONAL SUPPORT GROUP

St David's Hall, Aphrasia St, Newtown.
First Monday of every second month at 12 noon.
Contact: Rev. Ian Parton, 5241 9344.

CENTRAL HIGHLANDS (Ballarat)

Wendouree Uniting Church cnr Webcona Pde & Grevillia Rd, Wendouree.
Meet every second Tuesday of the month at 1pm.
Contact: Ms Rochelle Thomas, 0408 129 243

NORTH-CENTRAL REGIONAL SUPPORT GROUP

Meet on the first Monday of the month at 11 am
at various venues in Bendigo.
Contact: Mrs Anne Janssen, 5439 5831.

LOCAL CONTACT PERSON

GIPPSLAND (Warragul)

Contact: Mrs Mavis Gallienne, 5623 2940.

GOULBURN (Shepparton)

Contact: Mrs Margaret Stewart, 5821 1947.

INNER EAST METRO

Contact: Mrs Sally Edwards, 9836 3689.

INNER SOUTH METRO

Contact: Mrs Trish Williams, 9866 8317.

NORTH EASTERN METRO (Wombats)

Contact: Ms Simone Delmo, 9408 5339.

NORTH EASTERN (Wodonga)

Contact: Miss Claire Shelley, 5726 1476.

OUTER SOUTH METRO

Contact: Mrs Hyacinth Godfrey, 9796 2997.

PENINSULA

Contact: Mrs Rhonda Brown, 5981 2774.

RICH RIVER REGION

Contact: Mrs Barbara Fitzpatrick, 5480 0082.

SOUTHWEST (Portland)

Contact: Mrs Pat Hawke, 5523 4962.

WESTERN DISTRICT (Hamilton)

Contact: Mrs Clarice Carter, 5572 3286.

Family Support Service

Since our last newsletter, several important events have taken place that provided opportunities for new learning and will add strength to our work with people with MND.

During June, the Family Support Services Team travelled to Sydney to attend the National MND Family Support Services Day and the 5th National MND Conference. Both of these meetings gave staff the opportunity to meet with colleagues working in a similar position in other parts of the country, discuss work practices, hear about new developments and return to their areas of work refreshed and invigorated.



The theme of the conference was Care, Advocacy, Research and Excellence. The plenary session contained addresses from three keynote speakers: a current carer, a research neurologist and a well-being therapist. If you are interested to read more about the conference presentations, visit the MND NSW website on www.mndnsw.asn.au and search for 5th National MND Conference.

To support the administration functions that are a daily requirement of our work, we have recently had two major changes to our electronic management tools. Several years ago Eric Ohlsen of Business Echo Melbourne, a friend and supporter of MND Victoria, built an electronic management system to assist with the management of Equipment Services.

Lately, Eric has once again generously given his time and skills and undertaken a major upgrade of this system. Eric has spent considerable time at a greatly reduced rate, firstly listening to what was required, then making the changes necessary to meet the desired outcomes. We are delighted with the result of this work and thank Eric greatly for his expertise, generosity and flexibility.

At the same time as the above work was taking place and after much deliberation we decided to commence using the Department of Human Services' electronic client management system CRISSP. This system is available for use by disability agencies throughout Victoria and is free of charge, a big plus. It is a secure web based system, which means that Regional Advisors are able to log in from wherever they are in

Victoria and access their individual work list and client records. Excellent training and support has been provided by the CRISSP team and within only two weeks of going 'live' on the first of July, all relevant information was entered.

Whilst the above changes provide important assistance in the management and accessibility of data these tools are only relevant if they enhance our ability to provide a high quality, effective and efficient service. The outcomes will be monitored over the next twelve months and the tools evaluated to ensure that these goals are met.

Julie McConnell
Manager Family Support Services

The Aids and Equipment Program (A&EP) Vehicle Modification Subsidy Scheme

A vehicle modification subsidy scheme is available for people with a permanent or long-term disability who meet the eligibility criteria of the A & EP.

A maximum subsidy of up to \$10,000 is available to assist with the purchase of prescribed vehicle modifications to suit individual circumstances. The vehicle modification subsidy is not available as a contribution towards the purchase cost of a vehicle but only towards the cost of any modifications that are required to be made to the vehicle.

Additionally, any application for funding must be approved *prior to purchase of the vehicle*. A & EP state that no applications will be accepted by A & EP after the purchase of the vehicle.

A & EP funding applications must be completed by an occupational therapist (OT). There can be a waiting period for response from OT's so when ringing to arrange an appointment with the OT, ask to speak with the Intake Service Coordinator. Explain you wish to speak with an OT to discuss funding via A & EP for a vehicle that you wish to buy that may require modifications, and explain the timelines. The OT will endeavour to ring you back and discuss the options open to you as soon as possible. You can also ask advice from your regional advisor if you are having difficulties contacting an OT.

For further information regarding the subsidy, please contact:

Vehicle Modification Subsidy Scheme
Aids & Equipment Programme
Ballarat Health Services
Freecall 1800 995 009
www.dhs.vic.gov.au/ds/aep
Email: vmss@bhs.org.au

From the Desk of the CEO

(Continued from page 1...)

The Association is very keen to expand the Care Foundation, to the point where we remove our reliance on government funding. The creation of entities like the Susie Harris Foundation, with a commitment from the people involved to raise and contribute funds into the future, will drive the Care Foundation towards its ultimate goal of \$10,000,000 invested and fighting motor neurone disease. Please contact me if you would like to discuss a similar idea, or to make a contribution to the Care Foundation.

Strategic Review – as part of State Council's ongoing efforts to ensure that MND Victoria is doing what people with MND need and want, we are in the midst of a review of our services. Undertaken by Kris Honey, a well-respected consultant to the disability and health sectors, the review has focused on our objectives and the views of members about what we are doing to achieve them. Kris has received input in relation to our current services, whether we should be doing more, or different, or doing less. State Council and staff are keenly waiting for the conclusion of the review and its associated report. State Council expects to have the report in August, and will advise you of the outcome.

Kris will also speak about her findings as guest speaker at the Association's AGM. (See AGM notice on this page).

Elections – annual elections are held for vacant positions on State Council. Each year, four positions become vacant due to the retirement of the incumbents. Councillors are eligible to renominate for election. The call for nominations, and a nomination form, will accompany the 2008/09 Annual Review which will be distributed in late September to all members, and in the October Newsletter. All members of the Association are eligible to nominate. We have a comprehensive induction program for people who have not been on the State Council before, and an extensive manual to guide State Councillors in their role. Please contact me or David Ali, Chairman of State Council, if you would like to discuss standing for election.

Raising Hell on the Mountain Top for MND
'Raising Hell' is a new fundraising/awareness event that involves walking from Thredbo to the summit of Mt Kosciusko in the name of MND. Penny Leemhuis lost a close friend to MND and decided that one thing she could do was raise funds and awareness. She has chosen Mt Kosciusko to symbolise the peak of public awareness about MND. This is a joint venture with MND NSW. If you are interested in participating,

would like to sponsor a walker, or simply want some more information, go to our website – www.mnd.asn.au - and click on the footsteps logo.

Walk to d'Feet MND – the annual Walk to d'Feet MND is being held at Princes Park, Carlton on Sunday 15 November 2009. We are looking forward to a huge turn-up to share our commitment to MND, raise funds for MND research, and to have a very enjoyable day. I will see you there!

Research – State Council is very pleased to advise that nearly \$190,000 has been invested in research activity either through funds provided to the MND Research Institute, or by awarding Nina Buscombe Awards to support attendance at training events and conferences. Four named grants have been funded, each valued at \$35,000, as well as funding to manage the advertising and selection process for the named grants and to fund the Research Institute to undertake ongoing work and provide reviews of research reported locally and overseas for us to share with you.

In closing, I would like to express my personal thanks to our volunteers and staff who do such a fantastic job in supporting the work we do. From fundraising to equipment provision, from reception to out on the road visiting people with MND, our volunteers and staff have done a fantastic job this year, and made my part as a member of the MND Victoria team a pleasure and a privilege.

Until next time
Rod Harris

Annual General Meeting

MND Victoria has the pleasure
of inviting you to attend the

28th Annual General Meeting

Monday 26 October 2009
11 am

at Arlington at Wattle Park
1012 Riversdale Road, Surrey Hills

Guest Speaker
Kris Honey

Kris is a well-respected consultant to the
disability and health sectors and will present the
MND Victoria Future Directions Review

RSVP by 16 October
(03) 9830 2122, 1800 906 632, or info@mnd.asn.au

Group Programs

There are several group programs that have been developed to support people living with MND. All of our programs are currently under review. However, where possible we will continue to run these programs whilst the review is in progress.

LIVING WELL

The next *Living Well* program is scheduled to commence in late **August**, with a day, time and location determined by the availability and location of the participants.

Living Well is an eight-week program designed for both people with MND and their carers. The two groups meet at the same time and place, but in separate rooms to discuss topics which previous participants have found difficult to discuss elsewhere. Some of the topics covered include: improving quality of life, different approaches to managing your health, retaining a sense of hope, examining options for living in a new way and the relationship between living and dying. These sessions are run by trained facilitators with each session running for two hours.

Please contact Rebecca on (03) 9830 2122 or 1800 806 632 to register your interest

GreenPC



Green Peripherals and Components, otherwise known as **GreenPC**, is a social enterprise initiative of Info-xchange Australia that provides services to low income people on a national basis. The objectives of GreenPC are to upgrade and Internet-enable outdated computers. Once a donated computer has been refurbished, it becomes available for distribution.

Green PCs are recycled personal computers that are refurbished and repackaged into usable, Internet-ready computers, and then made available to low-income communities, individuals and community organisations.

The only qualification for an individual or family to have access to a Green PC computer is that they be holders of current Health Care Cards or are able to verify their low income status in some other way.

If you have any further questions, please call Green PC on (03) 9418 7400

KNH CONSULTING PTY LTD

Dear MND Members,

I am writing to thank you for your strong support of the review I am undertaking to inform the future directions of the MND Association of Victoria.

While focus groups weren't the way many of you wanted to provide input into the review, I received a large number of responses indicating people were happy to provide feedback either in writing, by email or through telephone contact. As a result, I have been able to add to the richness of the information provided through previous surveys undertaken by the Association. For those of you whom I wasn't able to get to - my apologies. The level of response and interest meant that I had to make some choices about who to contact.

What struck me in talking with members was the generosity of your contribution. I was aware, that in order to provide comment on the Association people were also having to reflect, to some extent, on their own journey with MND, either as a person with MND, a carer and/or as a volunteer. Given, that each person undertakes that journey differently, it meant some people were eager to talk while for others it meant reflecting on something that as one person said to me they don't want to know anything about.

I want to thank those who spoke with me for your time and your observations, and particularly acknowledge those for whom the review input stirred personal reflection.

By the time you receive the newsletter containing this letter, the review should be close to finalisation or be with the State Council for consideration. I would expect that the next newsletter will contain an article on the key themes of the review.

Again, to all those who offered and to those who did provide input into the review - Thank you

Kris Honey
KNH Consulting Pty Ltd

Access Travel Pass

The following information is drawn from a media release issued on 23 June 2009 by the Victorian Minister for Public Transport, Lynne Kosky.



People who have a severe and permanent disability and can travel independently on public transport will have access to a new travel pass.

Public Transport Minister Lynne Kosky said there has always been a small percentage of public transport users who have always been unable to use ticketing machines and the new pass would give them piece of mind.

“The Brumby Labor Government is taking action to stand up for vulnerable Victorians and to give them access to public transport services and this pass will be made available to a small group of people who have a severe and permanent disability,” Ms Kosky said.

“This includes people who are in a wheelchair and have limited fine hand movement, which stops them from being able to reach a ticket machine or barrier, as well as some people who have an intellectual disability”.

“Following consultation with a number of special interest groups we have decided to close this gap by introducing the new Access Travel Pass. This new pass will be used in same way that people currently use the Vision Impaired Travel Pass. Pass holders will need to carry it when ever they use public transport and it will entitle them to free travel.”

The application process for the Access Travel Pass will include a number of steps:

- A registered health professional will need to certify that the applicant can travel independently but cannot use tickets; and
- All applications will be reviewed by an independent panel.

“While we anticipate that the number of people who will be eligible for this pass will be relatively small, it is important that we do all we can to make public transport accessible for all Victorians,” Ms Kosky said”.

“The Access Travel Pass will give more Victorians the freedom to travel when and how they want.”

Ms Kosky said the introduction of the Access Travel Pass would be timed to coincide closely with the roll-out of myki (the new ticketing system) in Melbourne.

“By introducing the Access Travel Pass at the same time as myki we can ensure that it forms part of the extensive staff training program that is now getting underway.”

Application forms for the Access Travel Pass will be administered by the Metlink Central Pass Office and will be available from the office or from www.metlinkmelbourne.com.au in September.



**You, your family and friends are invited
to an Information Night on MND**



Monday 10 August 2009

7 pm - 9 pm, MND Victoria

**265 Canterbury Road
Canterbury**

Information Nights are informal evenings intended to provide information about motor neurone disease for family and friends of people who have recently been diagnosed. People with MND are welcome as well.

The location of these sessions is flexible. If you have a large family group please let us know, and we may be able to come to a place near you.

If you would like to come along, please RSVP by Friday 7 August. If you want to register an expression of interest for a session at some other time or location, please contact Inez van Polanen:

Telephone: (03) 9830 2122 or Freecall 1800 806 632

Email: info@mnd.asn.au

Note: If you are unable to come to this session, the next Information Night will be on 28 September

Deon spreads the word

Over the past year or so, my nine year old son Deon has often spoken to me about making a speech at his school (Gardenvale Primary School) to raise awareness of MND. So during MND week in May, he did just that.

He and his very close friend Carly Schwartz, stood together at their school assembly and spoke to the children and teachers about the disease.

Deon spoke of his own father's illness and how his dad lived at home until he could no longer be cared for and needed to be cared for better at Bethlehem hospital. He told them it was important to "raise money for MND so that a cure may one day be found".

During the week, he and his friends sold wristbands, pens and cornflowers and raised \$1,148. His dad (my husband, Michael Jacks) passed away in December 2008.

Leora Jacks

Glass Half Full: Living with Motor Neurone Disease

This 27-minute DVD is part of the Glass Half Full Series, a Rick Searle Production made in association with Karuna Hospice Services and MND Australia. It features Tony & Dot Hynes and Tom Harley, Captain of Geelong Football Club.

The documentary provides a rare insight into an inspiring person's life, his family, his support team and his disease. He openly invites you into his home and shares his journey with honesty and humour.

The DVD costs \$15 plus \$5 postage and can be ordered via Karuna's website at www.karuna.org.au or from:

Mandala Books,
PO Box 2020, Windsor, Queensland 4030.
Tel: (07) 3632 8380
or email info@mandalabooks.com.au



Deon & Dad

To whom it may concern

I'm sure this project involved many, many people, to whom I wish to send my sincere congratulations.

To be completely honest I was oblivious to the making of the advert, though it's been a while since I have glanced at the Association's newsletter where there may have been a mention.

Therefore, when I first saw the advert screen, I experienced a mixed bag of emotions, initially fear around my own life span of 1 - 5 years now I've lived with motor neurone disease for four and a half years. However, this fear soon turned to immense joy as I witnessed a great awareness raising campaign, for motor neurone disease, on the television. On the television!

Thank you to absolutely everyone involved, at every level, from across organisations and businesses.

Thank You.

Robert Attwood
MNDA Member

The advert to which Robert refers is a 30-second long community service announcement, drawn from the Australian DVD called 'Glass Half Full', and distributed by MND Australia. See more information about the DVD in the previous column.

Research & Developments in MND

National MND Conference, June 2009

The past two decades, beginning in the 1990s with the decade of the brain, have witnessed a surge of interest across the motor neurone disease landscape, both locally and internationally.

Advances in our understanding of the glutamine neurotransmitter system and the discovery of causal genes linked to the development of familial motor neurone disease (MND) have re-ignited research interest. Problems related to clinical heterogeneity have been identified – not all MND is equal. It has become clear that survival in MND is determined by many factors, including the clinical presentation (phenotype), rate of disease progression, the early presence of respiratory failure and the patient's nutritional status.

Further improvement in survival seems dependant on improving our understanding of the pathogenesis of MND, leading to the development of early and specific diagnostic methods and the discovery of therapies that not only slow the progression of the disease, but also address the secondary consequences of respiratory failure and malnutrition.

In terms of key needs to facilitate future clinical trials and thereby treatments, without a definite test to diagnose MND, neurologists are hampered by continuing to rely solely on purely clinical criteria for diagnosis.

While newer imaging techniques have shown promise in aiding diagnosis, the role of imaging at present remains primarily to exclude other conditions. The development of novel biomarkers to objectively assess disease progression will greatly refine treatment trials (and significantly reduce trial costs).

In addition, the power of population registries such as the Australian Motor Neurone Disease Registry are being increasingly recognised. This local registry forms part of a growing worldwide trend to obtain epidemiological and natural history information for motor neurone disease, and provides a hub for collaborative approaches.

These collaborative endeavours will inevitably lead to a better understanding of MND, its progression in different patients, and to the development of guidelines for improved care of MND patients. As inevitably occurs with greater research focus, the potential for new therapies and approaches are being realised. In contrast to the previous century of limited progress in the field of motor neurone disease, these more recent developments offer realistic hope that new treatments will emerge.

Matthew Kiernan, Prince of Wales Hospital, Multi-disciplinary Motor Neurone Disease Clinical Service, Prince of Wales Medical Research Institute, Sydney NSW.

What is the cause of MND?

There are now three genes which are known to cause MND. These have been identified mostly in familial MND, but a few people with no family history of the disease have also shown a genetic cause. However, in over 90% of people with MND, the cause is still unknown.



Researchers around the world, including in Australia, are looking at genetic, physiological, biochemical, environmental and lifestyle factors which may contribute to the risk of developing MND. Results of these studies are published every week.

The Australian MND DNA Bank continues to collect blood and other tissue samples from people with MND to provide researchers with DNA to identify other genetic causes. They also collect environmental data from questionnaires and clinical data from neurologists' reports. Samples from some family members and from non-related people who do not have MND, are also needed for comparison.

They need as many people with MND as possible to participate in this research.

If you would like to contribute a blood sample to the Bank, please contact Inez van Polanen:

Telephone: (03) 9830 2122 or Freecall 1800 806 632

Email: info@mnd.asn.au

MND Research Tissue Bank of Victoria Annual Progress Report 2008

This report outlines several outcomes of the MND Research Tissue Bank of Victoria (mndRTBv) as a result of the support from the MND Research Institute of Australia (MNDRIA).

Summary report of the mndRTBv activities for communication to the MND Community.

The mndRTBv was established in 2003 as a repository of fluids (blood and cerebrospinal fluid (CSF)) and brains and spinal cords obtained from people diagnosed with MND. From these samples, the neuropathologist is able to confirm diagnosis of the illness. More importantly, these samples are used for research purposes which may lead to improvements in diagnosis, the development of early diagnostic tests, therapeutic interventions and the development of preventative strategies.

Continued on page 9...

Research

MND Research Tissue Bank of Victoria, Annual Progress Report 2008 *(Continued from page 8...)*

The bank has a total of 27 MND brain and spinal cord donations, four control 'normal' brain and spinal cord donations as well as a number of cerebrospinal fluid and blood donations. Tissue has been provided to 13 new and continuing research projects with research being conducted by research groups at The University of Melbourne, Howard Florey Institute and The University of Sydney. In the past 12 months this research has resulted in 10 Australian and international scientific publications and presentations.

The funds received from the MNDRIA have assisted the mndRTBv to maintain and expand the collection, and with associated tissue processing costs.

The mndRTBv would like to acknowledge the generosity shown by the donor and donor families in donating tissue to the mndRTBv. It is an act of great foresight and kindness to give at a time of loss, so that others may be helped in the future.

Registered potential donors to date:

- 13 MND brain and spinal cord registrations (6 new registrations)
- 12 Control 'normal' brain & spinal cord registrations (1 new registrations)

We continue to work towards increasing the number of blood, cerebrospinal fluid, brain and spinal cord donations through increased dissemination of information. Avenues for raising awareness are through announcements in the MND Victoria newsletter, via clinicians, word-of-mouth, and a brochure that has been devised for potential donors.

For more information or to register as a tissue donor, please contact Fairlie Hinton.

Ms Fairlie Hinton
 Coordinator MND Research Tissue Bank
 National Neuroscience Facility
 Level 3, 161 Barry Street
 Carlton South 3053
 Telephone: (03) 8344 1900
 Mobile: 0438 530 372
 Email: fhinton@mhri.edu.au
 Website: www.mndtissuebank.asn.au



Hand & Foot Massage

Our trained massage volunteers are now up and running doing simple hand and foot massages. Feedback from people with MND has been very positive. This simple hand and foot massage is provided in people's own homes.

We would like to invite more people with MND to try this service. If you are interested, please contact your regional adviser or call me to request a time. Please contact Prue on:

(03) 9830 2122 or 1800 806 632

Prue Gilligan, Coordinator of Volunteers

Feeling too cold? Too hot?

One of the problems caused by reduced mobility is a tendency to feel the cold, and hence to want the heating turned up high. This can sometimes be a problem when it results in the environment being too hot for other, more active members of the family.

One possible solution is a heated throw rug. Sunbeam has produced a rug which functions like an electric blanket, but can be used like a regular throw rug, on a lounge, armchair or bed.

The rug measures 1200 x 1600 mm and is made from plush microfleece. It can be machine washed and tumble dried for convenient care.

The rug features an illuminated control with nine heat settings, and is priced at around \$90 to \$100.

Obviously, care should be taken when being used by a person with limited mobility, or cognitive impairment. It might also be useful to discuss its possible use with health professionals involved in the provision of care.

Free haircuts for men or women



Enjoy the gentle touch of someone who knows the power of a good hair cut.

Marie, a retired hairdresser with experience in both teaching hairdressing and running a salon, will come to your home on Wednesdays (most metropolitan areas)

To make an appointment please contact your Regional Advisor.

MND in the Media

Radio

29/06/09 – 07/07/09: 3BA FM / Power FM, Ballarat, Raising hell on the mountain top for MND

3BA FM / Power FM, Ballarat, Raising hell on the mountain top for MND and audio of the award Penny Leemhuis received (air time for a month up to six times a day).

Newspapers

May 09: *Bendigo Miner*, Raising awareness of crippling disease



06/05/09: *Ballarat News*, Cork Donations

07/05/09: *Robinvale Sentinel*, The story of Peter and Michelle Everett and MND

28/05/09: *AAP International News*, SCI: World first: Japanese scientists create transgenic monkeys

28/05/09: *The Age*, Green monkeys under ethics spotlight

29/05/09: *The Australian*, With \$6bn on hand, benefactors need some easier guidelines - AMSR: The Australian Society For Medical Research

June 09: *Melbourne Weekly*, Corker of a cause

01/06/09: *AAP PR Releases*, Media Release: Daval International Ltd re AIMSPRO®

19/06/09: *Herald Sun*, promoting 'Benatas at Home' care – featuring Bob Grbin

19/06/09: *Ballarat Courier*, Penny aims high to raise awareness

22/06/09: *The Advertiser*, Music for MND

25/06/09: *Bendigo Miner*, Music day to fight against disease

04/07/09: *Herald Sun*, Melbourne pro-euthanasia doctor says: "I helped dying man to his end"

Magazines/Journals

Winter 2009: *The Ruyton Reporter*, Their brilliant careers: Judith Durham

Internet

June 2009: ABC news online, Euthanasia bill faces more scrutiny

The Outer Eastern Support Group

has pleasure in inviting you to the

Eight's Sunday Luncheon

August 2009

12.30pm

(Doors open 12 noon)

Cost: \$27.50 per person

(Children under 12 years, order separately)

Please come along and enjoy a meal with friends whilst raising funds to support people living with MND

Bookings essential
Closing date 25 August

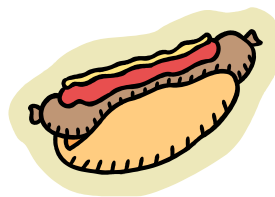
Contact: Marian Lowe

10b Royalden Close, Boronia 3155

Telephone: (03) 9762 9429

Email: marian_lowe@hotmail.com

Sausage Sizzle



Saturday 5 September 2009

Stop by and have a sausage
outside Bunnings at

230 Burwood Road, Hawthorn

A tasty and easy way to help support people
living with MND

Fabulous Fundraising

So far the shifting economy has not had any adverse effects on our fundraising. We have had some excellent results this year.

Thank you to all who support us so generously. Each year gets better and better and that means services are of the highest quality, responsive and meet changing needs because of your support.

So many ways to support us and so much support! The *Donor Update* keeps you informed and also allows you an opportunity to give during the year. This last year the *Update* has raised over \$40,000 towards services.

The next Spring *Donor Update* will be mailed in the first week of August. It will feature the special needs of young people living with MND, and as supporters of MND Victoria through their own fundraising in school and much more.

In the last three months we have attended community fundraising events such as the Judith Durham recital with other tin-shake volunteers, and the Ball held at Powerhouse in June in honour of Mick Roger. In the last year, events raised almost \$200,000. There are seven more events listed with us in the next six months.

Our current Tax Appeal has been a knockout! We shared the campaign with MND NSW, who used our letter also, to save costs for both organisations. The letter told the story of Jackie Mears and her brother as examples of young people as carers living with MND. To date, MND Victoria has received over \$63,000 and MND NSW received an amazing \$97,500 dollars. Donors expressed how moved they were by the story about young people who are carers. The Victorian Appeals raised more than \$90,000 this year.

We still receive great support from Trusts and Foundations towards equipment purchases and our family support programs. This year, we were able to help Tasmania establish their own Family Support Service for about 40 people living with MND.

Thank you to the families who have made bequests to the organisation. These are invested for longevity in the Care Foundation and will provide ongoing financial support for many years to come.

This year also saw more speaking engagements, with volunteer speakers accompanying me to tell their personal stories of life with MND. They have been

very moving, and encouraged further giving to MND Victoria from clubs such as the Freemasons and Lions. Thank you to those who were so willing to partner with me.

Let's not forget the valuable donations made through in-memory gifts, purchasing our merchandise, recycling thousands of corks, and so many general donations of heart-felt gifts.

We continue to actively support research and forward any donations specifically made for this purpose.

See you at the Walk in November. If you would like to hold an event in support of our work, I am happy to help you get started and support you where I can.

With sincere thanks for another great year.

Indira Kennedy
Fundraising Coordinator

MND Thank You Oh What a Night x 2

What a terrific night! We were blown away by the generosity displayed in every sense. A night like the MND Ball does not happen without heaps and heaps of contributors, so to all - thank you from the bottom of our hearts. Raising approximately \$50K was beyond our expectations.

As Mick said in his honest yet humourous address to us all, the main thing that helps him each day as he lives with this insidious disease is hope - hope that there will be a cure. Thanks to your generosity we are able to finance and promote research into just that - finding that miraculous cure.

Special thanks to the Trio and the Band, Chrome Donuts, who generously donated their musical talents and had the place rocking 'til the end (they are available for gigs).

For those who were not able to be there on the night and would like to donate to our MND cause, please find attached the link to the 'mycause' charity website that has been set up for the fund-raising ball:

www.mycause.com.au/fund_preview_page.php?id=422

All donations are greatly appreciated.

Thanks heaps for your support and contributions and for helping us to bring Mick's miracle that little bit closer.

Steve, Russell, Louise



Creating Awareness For Motor Neurone Disease

Many thanks to all the zo-èè sponsors and the 400 guests who attended Motor On 2009. For photographs of the night and details for Motor On 2010 along with other zo-èè events visit

www.zo-ee.com

Motor On 2009

Another Success Story! \$48,552 was raised for MND Research, bringing the total raised by zo-èè to over \$115,000 for MND research.

Motor On just keeps getting better and better and 2009 pushed all the buttons.

Karen Mustica and her committee of experienced and energetic players continue to enhance their capacity to deliver a wonderful night. The quality and range of silent and loud auction items donated by zo-èè sponsors was amazing, adding to the buzz that zo-èè functions always generate.

The Trust was a very stylish and exclusive venue. Victorian elegance combined with prompt and efficient bar staff, delicious finger food and the attendees dressed to the hilt and ready to party.

Entertainment by Jessi London and Tim DiStefan kicked the evening off and was followed by The Solar Flares pumping the room into dance action. In the "quiet" room, bar service flowed while the board selection of silent auction items were perused, valued and bid for. Driving prices was the passion to take home some highly desired items and the knowledge that all funds raised were supporting research into MND.

An introduction by Tony Schibeci about MND and his family link to the disease set the scene, and a short speech from Rod Harris (MND Victoria CEO) highlighted the recent discovery of the FUS gene – a major step forward in the MND research that had come from research funding provided by events like Motor On and zo-èè.

And then it was over to Simon Kinnersly from Grey's online to present the 'loud' auction items, generously provided by sponsors. All items sold well and the funds contributed considerably to the proceeds for the night.

With formalities over, DJs Derek K and James Belias delivered some great music and people danced the night away. An evening enjoyed by all!

Hope to see you at our next event!

BackSpin Trivia Night

ZO-EE will host the
Greatest Music Trivia Show In The Universe

along with Trivia Hosts
Grand Master Baitz & TJ Hooker

The boys will test teams of up to 10 in
Old School to New School Music Trivia!

When: Thursday 20 August 2009
Where: Prince Alfred Hotel,
355 Bay Street, Port Melbourne

Cost: door entry \$25, door entry & meal \$50
(meal and drink - tap beer, house wine or soft drink)

Doors opens at 6:30pm, Show starts 7:30pm

Ticket sales, please call:

Karen on 0414 538 133 or Gina 0411 567 810

or visit www.zo-ee.com for more details

All tickets need to be pre-purchased

The zo-èè team





The Freight & Shipping Industry Charity Ball 2009

Proudly supporting MND Victoria & Calvary Health Care Bethlehem

MND is in need of funding for research and family resourcing. With greater funding, researchers can build upon their very positive recent work in this area, and families can access necessary equipment.

Join us for a fun night that will also make a very big difference.

When: Friday, 18 September 2009, 7.00pm till Midnight.

Where: Atlantic Group Peninsula, Shed 14, Docklands, Melbourne

Dress: Black tie with tables seating 10 or 12 as required

Cost: \$145 per head, includes drinks on arrival, plus a superb three-course dinner, entertainment and drinks including beer, wine and soft drinks.

A Touch of Blue

The night includes a full floorshow and entertainment, featuring: The Royal Australian Navy Band, comedians Elliott Goblett (Jack Levi), Dame Edna Impersonator (Mick O'Neill), Cath Jamison (Magician of the Year) Elvis and Austen Powers Impersonator (Mark Andrew). Special Guests: selection of Melbourne's Premium Entertainers, including Melissa Nance and Gilbert Ernest plus many other artists to be confirmed.

A raffle and major auction will be hosted by Melbourne Auctioneer Bill Wellwood plus a silent auction featuring a range of valuable items. The raffle will be drawn at 9.00pm, then dancing until midnight, come along, enjoy !

**For more information or to book a table
contact Dawn Nance on 0414 773 008**

'Drive to the Door' Valet parking is available on request at \$25 per car and can be pre-booked via:
<http://www.ballsatnight.com.au/index.cgi?act=menu&i=41>

Calling All to the Summit of Mount Kosciusko

Raising Hell on the Mountain Top for Motor Neurone Disease (MND)



'Raising Hell' is being held to raise awareness and funds for MND NSW & MND Victoria. By becoming a 'Hell Raiser' you can have an impact on MND.

"We all walk our mountains in life, this time let's take it to the mountain top together for MND"

When: Sunday 22 November 2009

Where: Mount Kosciusko, Australia's highest peak

For more information visit

www.everydayhero.com.au/event/raisinghell, or www.footprintsofyourlife.com



DONATIONS WERE RECEIVED IN MEMORY

Jan Barrett
Peter Barrett
Geoff Blake
Ross Bradfield
Ken Brentwood
Chris Buzina
John Byrne
Eric Collier
Marie Cunningham
Domenico Di Biase
Pasquale Di Fabio
Peter Downey
Sid Drew
Bernie Drummond
Simon Gardiner
Richard Gillett
Johanna Glaubitz
Helen Greely
Brian Halliday
Arthur Harris
Jean Harris
Joan Harris
Robert Hudson
Joy Iggulden
Lella Jenkins
John Kingdon
Peter Lowe
Daniel McAuslan
Patricia McMillan
Margaret McSwan
Peter Meehan
Mario Molinaro
Tony Page
Fred Panknin
Kerrie Pitkin
Alex Pollock
Ron Roney
Max Rouget
John Ryan
Patrick Ryan
Margaret Seaward
Peter Smith
Tom Smith
Neil Sorensen
Jan Soward
Jim Whitford
David Williamson
George Wilson
Guy Winkley

**DONATIONS IN MEMORY
RESEARCH/EDUCATION:**
Norm Henkel
Don Walker

GROUP DONATIONS:

All Souls Opportunity Shop
Brighton Coronation No 122
Christian College Geelong
Green Acres Golf Club
Kring Nieuw Holland
Lioness Club of Trafalgar Inc
Lions Club of Beaumaris
Lord Somers Australasian Chapter 1
MFB General Office Social Club
Rotary Club of Mont Albert &
Surrey Hills
Rotary Club of Tatura
Sportsmans Association of Australia
St Michael's Uniting Church GCC
The Monash-Aires
Tuscan Lodge No 241

CORPORATE DONATIONS:

Construction Engineering P/L
Hamlan Homes P/L
Kaos Custom Bikes
Maroondah City Council
Moore Stephens Melbourne P/L
RJ Waller Customs Brokers P/L
TP Weichmann & Associates P/L

TRUST DONATIONS:

Dimmick Charitable Trust
Edward Wilson Trust
IOOF Foundation
Joe White Trust
Spencer Investments P/L
The GW Vowell Foundation Ltd

BEQUEST DONATIONS:

Estate of the late:
- Catherine Frances Manning
- Elizabeth Vaughan
- Heather Rosalind Winton



Thank You to everyone supporting the work of MND Victoria by memorial donations in lieu of flowers.

Donations are promptly acknowledged to families and to individual donors.

Photos make a difference for MND Eight (8) more photos needed

The ALS March of Faces Banner, begun in 1997, is a travelling exhibit in the USA that features a 170-foot photographic display of people with ALS/MND from all over the world. The Banner idea was introduced to Australia as "Australia's March of MND Faces" Banner. If you would like to see the Banners, visit MND Victoria's website at www.mnd.asn.au and click on the link to the banners which can be found on the right-hand side of the home page.

It's not too late for you to be a part of this exceptional photographic project to advance MND Awareness. Photographs are continually being gathered for the preparation of new banners. There is no better way to raise awareness about MND than by making the general community aware of the many people personally impacted by it.

We only need *eight* more photos to make the next banner

You are welcome to include family or caregivers in the photo if you wish. In addition, a March of Faces Form needs to be filled and returned to MND Victoria. Please contact Inez van Polanen at MND Victoria if you would like more information or a registration form, or you can download the form from the website.

Contact Inez van Polanen at:

Telephone: (03) 9830 2122

Freecall 1800 806 632

Email: info@mnd.asn.au

If you are unable to email, please send the form and photo by mail to MND Victoria, PO Box 23, Canterbury 3126.

CONTRIBUTIONS TO THE NEWSLETTER ARE INVITED

MND Victoria members are invited to contribute personal stories, anecdotes, letters, questions to "Ask the Experts" or "Handy Hints" to the Newsletter. We cannot guarantee that all contributions will be published, depending on space available, but every effort will be made to do so. Please note below, the dates by which contributions should reach the Newsletter Editor, MND Victoria, PO Box 23, Canterbury 3126 or email info@mnd.asn.au

NEWSLETTER ISSUE	COPY TO EDITOR BY	NEWSLETTER MAILOUT DATE
Sept - Oct 2009	11 September 2009	6 October 2009

DISCLAIMER

The content of this Newsletter is provided for information purposes only. It has been reviewed to support its accuracy by appropriately qualified and experienced people. Information is provided on a range of organisations providing services which may be of interest to people living with MND. Inclusion of information about particular organisations or services should not be construed as an endorsement of those organisations or services in preference to others, nor as a recommendation as to the value or quality of the organisations or services mentioned. The Association does not accept any liability to any person for the information or advice (or the use of such information or advice) which is provided in the Newsletter or incorporated into it by reference. The information in the Newsletter is provided on the basis that all persons accessing it undertake responsibility for assessing the relevance and accuracy of its content for their own purposes. Before taking any action, competent medical advice should be sought.

MND Victoria Membership/Renewal Form

TITLE FIRST NAME SURNAME

ADDRESS

PHONE EMAIL

Name of person completing the form and who can be contacted on my behalf

PHONE EMAIL

RELATIONSHIP SIGNATURE

Membership Category (Please tick box)	√	Membership is free to people with MND who live in Victoria or who receive services from MND Victoria, (e.g., members of border Support Groups)	
I have MND (Membership Free)		FREE	
I have MND (living Overseas)		\$20-00 per year	\$20 - 00
General Member/Supporter		\$20-00 per year	\$20 - 00
Health Professional/Service Provider		\$20-00 per year	\$20 - 00
Organisational Membership		\$20-00 per year	\$20 - 00
I enclose a donation towards the work of the Association (All donations over \$2 are tax deductible)		DONATION	\$
		TOTAL PAYMENT =	\$

METHOD OF PAYMENT (Please tick <input type="checkbox"/>)	CASH <input type="checkbox"/>	CHEQUE <input type="checkbox"/>
CREDIT CARD	VISA <input type="checkbox"/>	MASTERCARD <input type="checkbox"/>

CARD NO

EXPIRY DATE / SIGNATURE

COMPLETE FORM AND POST TO:
MND Victoria, PO Box 23, Canterbury 3126
(Street Address: 265 Canterbury Road, Canterbury 3126)

Tel: (03) 9830 2122 Freecall 1800 806 632 Fax: (03) 9830 2228
Internet: www.mnd.asn.au Email: info@mnd.asn.au
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