



February 2011

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## From the Executive Officer's Desk

It is hard to imagine that four weeks ago I was holed up in an apartment in Brooklyn while a blizzard raged outside the windows dropping about two feet of snow on New York. The snow only delayed me one day before I was out paddling and slipping around in the snow to continue my Christmas and New Year adventure in New York. New York, New York is certainly the place to be at that time of the year. I was on the edge of Time Square just before the ball dropped at midnight to welcome in 2011.

A new year, eh? On the way to the new year, I went to the International Alliance of ALS/MND Associations meetings and Symposium in Orlando, Florida. I thank the MNDAWA Board for support to attend, and acknowledge the funding from the Nina Buscombe Award provided by MND Victoria (EO Rod Harris), and assistance from Curtin University WA Centre for Cancer and Palliative Care (Prof. Samar Aoun).



My theme for this edition is "imagine". Imagine what could be for us as individuals, as an organisation and as a society. I picked up this theme from the International Alliance of ALS/MND Association's meetings. The culture of the Alliance is all embracing ... inclusive of professionals, patients, carers, volunteers, therapists, and

scientists who are trying to understand ALS/MND and care for those with MND/ALS.

On the tables at the meetings were some red envelopes, within which was a Christmas card made by Linda Sepulveda (coordinator of the ALS clinic and research centre at UCLA). At



David Ali (MND Vic), Graham Opie (MNDNSW) and Sue Colyer (MNDAWA) at the International Alliance meeting. [Translators and IT technicians in background]

first I didn't realise that the heart pinned to the card was handmade and this was confirmed when I asked Linda. She had made several hundred hearts to attach to the cards that contained the following message for the delegates from the 30 nations represented at the Alliance meeting:

*Imagine ... anyone in the world could develop ALS/MND*

*Imagine ... there are ALS/MND patients in this world who don't have access to experienced health care professionals.*

*Imagine ... a world without suffering.*

*Imagine ... that ALS/MND International Alliance is there for all people all over the world.*

*Bless you this holiday season for your gift to ALS/MND patients around the world.*



This message captured what I experienced at the International Alliance meetings, the Allied Professionals Forum and the International Symposium amongst about 1000 delegates, as well as more than 300 poster presentations on research activities. Fellow delegates were interested, supporting and determined to do their best whether as researchers, medical professionals or carers and educators to alleviate the impact of ALS/MND. It was an overwhelming spirit.

Carol Birks, National Director, MND Australia, wrote a very comprehensive review of the content of the three components of the meetings and symposium, which I have placed on our



## MND Upcoming Events Diary

	Event	Date	Time	Venue
<b>F e b r u a r y</b>	Craft Group	Thurs 10 Feb 2011	10am-2pm	The Niche - Passmore Room
	MND Volunteers Meeting	Thurs 10 Feb 2011	10:30-11:30am	The Niche - Passmore Room
	Helfgott Plays The Classics	Sat 12 Feb 2011	6:30pm	For more information please call the MND office on (08) 9346 7355
	Carers Lunch	Tues 22 Feb 2011	11:30am-1pm	The Niche - Boardroom
	'Pillows and Postures for Fatigue Management' workshop	Thurs 24 Feb 2011	10am-12:30pm	The Niche - Passmore Room
	Past Carers Group	Thurs 24 Feb 2011	2pm	410B Marmion Ave, Melville RSVP attendance by 23 February to Corry Fisher on (08) 9330 1735
	Pamper Day	Sat 26 Feb 2011	11:30am-3pm	The Niche - Boardroom RSVP attendance to (08) 9346 7355 or admin@mndawa.asn.au
<b>M a r c h</b>	<i>Labour Day Public Holiday</i>	<i>Mon 7 Mar 2011</i>	<i>MND Office will be closed</i>	
	Craft Group	Thurs 10 Mar 2011	10am-2pm	The Niche - Passmore Room
	MND Volunteers Meeting	Thurs 10 Mar 2011	10:30-11:30am	The Niche - Passmore Room
	Carers Lunch	Tues 22 Mar 2011	11:30am-1pm	The Niche - Passmore Room
	Past Carers Group	Wed 23 Mar 2011	11am	Mandurah Dome Cafe – take the shuttle bus from the train station and to get dropped off at Dome. RSVP attendance by 22 March to Heather Jopek on (08) 9314 3863
<b>A p r i l</b>	Craft Group	Thurs 14 Apr 2011	10am-2pm	The Niche - Passmore Room
	MND Volunteers Meeting	Thurs 14 Apr 2011	10:30-11:30am	The Niche - Passmore Room
	Carers Lunch	Tues 19 Apr 2011	11:30am-1pm	The Niche - Boardroom
	<i>Easter and Anzac Day Public Holiday</i>	<i>Fri 22 – Tues 26 Apr 2011</i>	<i>MND Office will be closed</i>	
	Past Carers Group	Thurs 28 Apr 2011	2pm	9 Stonefield Crt, Padbury RSVP attendance by 27 April to Els Burggraf on (08) 9307 5521



### Nifty's February highlights...

#### Craft Group

Thursday 10 February 2011  
10am - 2pm  
The Niche - Passmore room

#### Carers Lunch

Tuesday 22 February 2011  
11:30am - 1pm  
The Niche - Boardroom

#### Past Carers Group

Thursday 24 February 2011  
2pm  
410B Marmion Avenue, Melville  
RSVP your attendance by 23 February 2011  
to Corry Fisher on (08) 9330 1735

### Pillows and postures for fatigue management in MND

**Thursday 24 February 2011**  
**10am – 12:30pm**  
**The Niche, Passmore Room**

Empowerment and enabling quality of life are an integral part of the MNDAWA role in the lives of the people we work for. Join Cindy Evans on Thursday 24 February at 10:30am for an Exercise Physiology based practical fatigue management workshop. People with MND, their primary carers and interested allied health professionals are encouraged to attend this information session.

Please contact the office on 93467355 to register.

## Care Advisor's Corner - February 2011

Hello Everyone. It's February and 2011 has well and truly started!

All the Care Advisors are back from their various breaks and at their stations ready to assist you all for 2011. We hope that you all had some time to share with family and friends or just kick back and enjoy the festive season.

Below are our **dates to remember** for February:

### **Cares Lunch**

**Date - 22/02/2011**

**Time - 11.30**

**Where - Boardroom @ The Niche**

**Speaker - Annabel Vasquez  
(National Relay Service)**

### **Pamper Day**

**Date - 26/02/2011**

**Time - 11.30 - 15.00**

**Where - Boardroom @ the Niche,  
Nedlands**



Karen Brown, Leah Firth and Leonie Lorian enjoy some friendly company at the December Carers Lunch.

### **Equipment Pool**

A reminder to those who have used this facility and to let those who are new to the Association know that as part of the service we offer at the Motor Neuron Association we have an equipment pool that holds a wide range of equipment from large items like electric wheelchairs to smaller items to assist with eating, drinking and personal hygiene. It always

pays to ask your Care Advisor about items that you may think of purchasing before making a purchase as we may have what you need in stock or might be able to acquire an item for you. This service is offered free to anyone who has a diagnosis of MND. It can be of great benefit as we often have different ideas that may be of assistance.

We are currently trialling some new equipment, including:

**Mega Bee** - A Hand Held Writing Tablet. An easy to use and rapid deploy hand held writing tablet for people who have lost the ability to speak. It is convenient and keeps communication between the member and their carer open and free. More information can be viewed on the internet under Mega bee Communication devices.

**Page Turners** - A desktop reading aid that gives the user freedom to continue reading for pleasure, research or business, providing a feeling of independence and staying connected.

Once it is set up with the book in place, it can be controlled by the reader through various methods such as with a joystick, multiple switches or scanning scheme. It can be used with both hard back or soft covered books and magazines.

**Smart link Personal Alarms** - A monitored system that allows the user to summon help when required. It has a receiver and a transmitter and is monitored 24 hours.

Take the worry and uncertainty away when you introduce a personal alarm system to your life. We have some base stations and neck pendants in our equipment pool, as well as large button telephones.

There is a small charge for the monitoring fees but if you ask your Care Advisor they will be happy to give you all the details.

**Slimline Key Safes** - A Key Safe for outside your door that operates on a password and number code.

This allows family, friends and nominated health officials access to your home at anytime. This device has proven beneficial on many occasions with other members.

**For your information: Advanced Health Directives (AHD)**

### **• Storage Advice and Alerting Public to AHD States**

When your Health Care Directive is completed you may wish to share this with your Family and health professionals as well as give them a copy. Keep one at your home were Care staff can familiarise themselves with your preferred wishes.

### **• Alert Public to your Wishes**

You may keep a statement card in your wallet reflecting that you have an AHD or you can have this information on your medical Alert Bracelet.

More information can be gained on the website for Public Advocate .

<http://www.publicadvocate.wa.gov.au/>

The MND Care Advisor at the Niche are available to take phone calls, visit you personally and access information on behalf of you. Our aim is to provide the best assistance we can to our MND Clients, their families and friends. So please feel free and comfortable to contact us - we love hearing from you all!

**Rose Gibbins  
MND AWA Care Advisor**

## **After Hours MND Assistance**

The Care Advisors suggest the following steps as a guide if you require assistance out of office hours:

### **MND Information and advice:**

- Call the after hours number 0439 918 052

### **For general health care needs:**

- Contact your locum GP for medical assistance.
- Attend your closest public hospital out-patient department, or
- Call Health Direct Australia on 1800 022 222

### **Emergency respite needs:**

- Contact Perth Home Care Services Crisis Care Services: 9244 5411

### **Emergency Health Care Needs:**

- Dial "000" and ask for an ambulance

For information on MND care, symptom management and support please visit

  
[www.mndcare.net.au](http://www.mndcare.net.au)

## Laughter Workshop

On 5 January 2011 MNDWA staff and a dedicated board member kicked off the new year with a team building exercise with a difference. The focus of the training was working together as a multidisciplinary team in harmony. Thanks to Laughterworks Australia for helping us learn how to do that by filling our work day with a very large amount of laughter and joy. *Can you guess who brought their own dress ups?*



Left-Right: Marie Macdonald, Sue Colyer, Samantha Wittle, Cindy Evans, Cherylyn Vickery and Raquel Rodriguez.

## MNDWA Volunteers Day

Thanks to all those wonderful volunteers who joined us for the first volunteer day for 2011. We heard some tales of the very first volunteers in WA, explored some of the ways that volunteers can make a difference to MNDWA, ate some pretty fantastic food and shared quite a bit of laughter and joy with each other. It was a very fun and educating day. For all those who missed out, and all those who want more, our next volunteers meeting for 2011 will be held in the Niche Passmore Room on Thursday 8 February 2011.



Rosa Lenzo and Heather Joppek share a few good laughs at the MNDWA Volunteers Day.

**Cindy Evans**

## Support our supporters!

The following companies offer a contribution from their sales to support the work of the Motor Neurone Disease Association of WA.

### Bluesky Healthcare

Enjoy extra discounts—If you mention MND when you make a purchase, you will receive 5% off and Bluesky will donate 5% to the Motor Neurone Disease Association of WA.

Call Bluesky Healthcare for your mobility needs 1300 65 1300



### Quality Printer Cartridges

For every Premium Plus cartridge that is purchased by customers who mention the MND Association, QPC will donate \$5 per cartridge to MNDWA for the lifetime of that customer.

A great opportunity for business and private use. Visit [www.qpca.com.au](http://www.qpca.com.au) to place an order or for more information.



### Wembley SUPA IGA

Join the Wembley SUPA IGA Community Support Card program and 1% of your grocery spend will be donated to MNDWA. Exclusive to Wembley SUPA IGA - located at 320 Cambridge Street, Wembley.

You can register in-store or on-line. Visit [www.wembleysupaiga.com.au](http://www.wembleysupaiga.com.au) for more information.



## Bluesky Healthcare

Manufacturers and suppliers of mobility equipment

- Electric mobility scooters
- Lift & recline chairs
- Adjustable beds
- Platform lifts
- Powerchairs
- Stairlifts

### ENJOY EXTRA DISCOUNTS WITH BLUESKY HEALTHCARE

**You get 5% off and Bluesky Healthcare donates 5%**

Simply mention MND Association of WA when you place your order and you will receive an **EXTRA 5% DISCOUNT** on all purchase, **PLUS** an additional 5% will be donated to MNDWA.



Call 1300 65 1300 for more information  
Servicing all areas of WA  
**1300 65 1300**

## Cash & Carry

**Get more in your trolley!**

[www.cashandcarrywa.com.au](http://www.cashandcarrywa.com.au)

**Support Motor Neurone Disease Association of WA every week with MY COMMUNITY!**

You can save on your grocery bill and support MND at the same time. Every time you spend at Cash & Carry a percentage of your spend comes to MND. Last year several hundred dollars was contributed by shoppers using the MND card (see below).

BALCATT A - 8 Geddes St Balcatta WA 6021

BUNBURY - 60-64 McCombe Rd Bunbury WA 6230

CANNING VALE - Baile Rd Canning Vale WA 6155

**Cash & Carry** MEMBERSHIP CARD

**Motor Neurone Disease  
Association of WA  
0036623007**

Cash & Carry are a wholesale warehouse supplying retailers / resellers, commercial, industrial and institutional users. Issue of this card is subject to the conditions of registration.



website. My report is more impressionistic of the research, the care services and other ideas.

Most overwhelming is the scope of research that is going on to unravel the mystery of ALS/MND. There are researchers in USA, Canada, UK, Switzerland, Belgium, France, Germany, Italy, Netherlands, Japan, India, China, and of course Australia, just to identify a few of the countries involved

in research. Many of the research projects are collaborative efforts between two or more research centres, universities and clinics. The scope of the genetic research is immense. I attended many of the genetic research presentations and came to understand the enormity of the search for the cause of MND/ALS. I list some of the points that I brought away from all the presentations:

**Genetic research is complex**

- Many chromosomes involved, with focus now on Chromosomes 9, 18 and 20.
- Up to 12 genes appear to be involved in Familial MND, and some of these now identified in Sporadic MND.
- Another 35 genes implicated in mutations, misfolding of DNA, and toxic effects.
- Many mutations have been identified with one gene – for example, 140 mutations identified in SOD1 that is associated with Familial MND.
- RNA (Ribonucleic acid) is now of interest in its processing role in protein binding and cell metabolism, particularly reflected in abnormalities in TDP-43 (a DNA binding protein) found in ALS.
- Other research is investigating the role of those non-neural cells that appear to have an abnormal function in MND patients.
- Animal models of the disease are used for research – flies (with which humans share DNA, similar cellular function and nervous system function), mice and rats.
- Only about 1% of DNA is decoded.

**Psycho-social research**

- Impact of MND on relationships and intimacy ignored.
- Advance care planning essential.
- End of life communications, religiosity and spiritual need to be part of care discussions.
- Education of care workers to understand needs of MND patient.
- Needs of carers – the other “patient”.

**Treatment issues**

- Shifting perspective of MND care: 1980 – “affairs in order”; 1990 – Riluzole and practice parameters; 2000 – Non-Invasive Ventilation (NIV), Percutaneous Endoscopic Gastrostomy (PEG); 2010 – earlier diagnosis, full continuum of care through clinics, and evidence based practice. ALS/MND – not curable, but treatable.

- There is now conclusive evidence that there is brain degeneration (both cognitive and behavioural) in about 50% of MND patients. This degeneration is similar to Frontotemporal dementia, which is the second most common form of dementia in people aged over 65 years.
- Moderate six month exercise program was associated with better function, and no adverse affects.
- The length of time for potential drugs to be identified, tested and released – 2 years to 10 years before a drug can be available on the market.
- Drug testing takes years but the message is more hopeful for ALS/MND patients, with a number of clinical trials advancing through the process; including many late stage trials.
- Stem cell treatments are viewed as extremely speculative, not a therapy, and any stem cell transplantation should do no harm.



**Technology**

- V o i c e banking – recording patient’s voice for use later in s p e e c h generating technology.
- S e l f assessment

functional scale.

- National register for ALS/MND patients to self register with personal details – for access by researchers.

The following web site hosts discussions of the presentations for those who may wish to pursue some of these matters - <http://mndresearch.wordpress.com/category/symposium/orlando-reporting/>

These brief notes do not do justice to the scope of the Alliance meetings and presentations. The tip of the iceberg! So there was much imaging about what all this research will find and when; what new treatments will become possible; how to improve care; promote the cause to raise funds for research and care services; new ideas to raise awareness; and how to get a multi-disciplinary/multi-care clinic for MND patients. What I did bring home is the message that huge progress has been made in the past years in research to understand MND, in new drugs being developed, and in approaches to care and treatments (not cures) that can provide comfort and support to the MND patients and carers. There was a spirit of hope pervading the conference meetings.

While walking in Central Park, New York, I found myself in Strawberry Fields, just across the road from the Dakota Building where Yoko Ono still lives. The photo on page one was taken at the Imagine Circle that is recognised as a memorial for John Lennon. We can all “imagine” in our own small way to make a big difference.

Wishing you and your families peace and hope in 2011.

Sue Colyer  
Executive Officer

*“You may say that I’m a dreamer  
But I’m not the only one ...”*

John Lennon 1971

## Gifts and Donations

### General Donations

Renate Wright  
Ruth Ruane  
Patricia Cleasby  
Dr Digby Cullen  
Bill Evans  
Michelle Bradshaw  
L B McKenzie  
Kaye Metaxas  
Graham Martin  
David Higginson  
Fen Hewitt  
Cedric Broun  
Maria Lenzo  
A Lindsay  
Melany Hall  
Corry Fisher  
William Preston  
Robbie Telfer  
James A Saxton  
Gwen Edward  
Eddie Froend  
Rita Colquhoun  
M Berg  
Reggie Lamb  
Cellarbrations Coolbellup  
City of Joondalup  
Woodside Energy Ltd  
Peel Foodbank  
Shannon Home Builders  
BankWest

Dept of Transport AIS/Defect Notice Section  
Old East Past Players and Officials Association

### Change 4 Change

Yvonne Abbott  
Amber Paskett  
John Wilkins  
N Van Der Snoek  
Janette Mary Gray  
Lesley O'Brien  
Cheryl Coates  
Fremantle CBC Football Club  
Southlake TAB

### Fundraising

MNDAWA Craft Group

### In Kind Donations

Thank you to our "In kind" contributors:  
**Dr Kandy James** - two communications workshops for staff

**Mr Fiddly Bits** (aka Peter Baker) - installation of notice board

**Back in Action** - massage for carers

### Bequests

The Estate of the Late Marjorie Cook  
The Estate of the Late Jessie Lorimer

### In Loving Memory of

#### *Stephen Brown*

- Karen Smart  
- Tina Altieri  
- Joy Diver  
- R Switch  
- B Fatovich

#### *Edith Mary Darvell*

- Michael Disisto  
- Julie Robinson  
- Ray & Sue Pryer  
- Sylvia Pryer  
- I Bell  
- Frank & Cheryl Borgogno  
- Kylie Direnzo  
- Kings Inn Chinese Restaurant  
- Stephen & Elizabeth Dalley  
- Anonymous

#### *Peter Godfrey*

- Diana & Gofrey Bodel

#### *Geraldine Manley*

- Croma Coatings

#### *Patrick Nolan*

- Evon Stewart

#### *John O'Connor*

- Audrey O'Connor

#### *Alan Whitfield*

- Terri Clancy

#### *Christopher R Sturgeon*

- Russell Phillips  
- Miranda Woodhouse  
- Mal Butler  
- Paul Robinson  
- Vanessa Marshall  
- Harvey Deegan  
- Noelene Harvey  
- Sara Lovell  
- Pat & Bob Stidwell  
- L Boyce  
- Belinda O'Reilly  
- Jodi Fitzgerald  
- Mike & Marg Malaxos  
- Jacqie Vandersluys  
- Geoffrey Barber  
- Dudley Younger  
- David & Jocelyn Munt  
- Mick & Von Healy  
- P Livingstone

#### *Michael Smith*

- Peter De Leuw

#### *Robyn Hornsey*

- Lisa Rechichi

#### *Michael Rodrigues*

- Bernadette Layzell

### Street Appeal December 2010

Many thanks to all the Volunteers who collected money and everyone else who helped out in other ways for our Annual Street Appeal held Friday 10 December 2010.

The total amount raised was \$2,627 - Well Done to everyone who participated!

*Lois Peck*

### Christmas Card Shop Volunteers

A big thank you to the Christmas Card Recognition team which included Rosa, Cheryl and her grandson Jayden, who volunteered their time to fundraise for MNDAWA by selling Christmas cards.

### Online donations



You can now access three online options for donating to MNDAWA from our website home page using

#### **MyCause**

#### **PayPal** and

#### **Everyday Hero** – go to

[www.everydayhero.com.au](http://www.everydayhero.com.au) and search Motor Neurone Disease Association of WA Inc

If you are running an event or participating in one, you can raise funds for MND by asking your supporters to make a tax deductible donation via Everyday Hero. If you are IT savvy, you can create you own donation page from the MND Everyday Hero page.

Luke Frapple is our first hero, who is asking people to sponsor his triathlon efforts. Thank you, Luke, for this great initiative. Do we have any more heroes out there?

### Bequests to MNDAWA

Your Will can be a convenient means for making a charitable gift of lasting value to the people and causes you hold dear. By making a bequest to MNDAWA you will help ensure that our efforts in making a difference to the lives of people living with MND continue into the future.

For information about bequest donations to MNDAWA, please contact the office on (08) 9346 7355 or [admin@mndawa.asn.au](mailto:admin@mndawa.asn.au)

The evening of Friday 14 January 2011 was the occasion of the fourth Maree Finlay Cup, held at Peelwood Reserve, Mandurah and organised by the Halls Head Cricket Club. A crowd of about 1500 people gathered at the pavilion and on the "hill" to enjoy the game played out in the warm afternoon sun and cool breeze. Spectators took advantage of the sausage sizzle and face painting for the children, and an MND merchandise stall.

and Rod Tregenza. The Honourable Dr Kim Hames, MLA, Deputy Premier; Minister for Health; Indigenous Affairs was also present.

The result was Mazza's Purple Chargers defeated the MND Blues by 2 wickets. Purple Chargers were 8/185 in the last over, to MND Blues all out for 184. Congratulations to Man of the Match, Ryan Campbell, who scored 34 runs from 15 balls. *[Australia could do with batting like this! Ed.]*

The funds raised at this cricket match support the Maree Finlay Community Bus that is managed by People Who Care in Mandurah. The Maree Finlay bus is a very visible and tangible outcome of the generosity and compassion of the Mandurah community.

Our sincere appreciation and thanks go to all who were involved as organisers, sponsors, players, and to all those who made a personal donation of time, energy and money to make this project a reality and the event another celebration of community.

Thank you to all the Sponsors and supporters

- Halls Head Cricket Club
- People Who Care
- Alcoa Australia
- Mandurah Retravisoin
- Cabling WA
- Midland Brick
- Terrace Art Framers
- Woolworths Miami
- Cafe Prontos
- Greyhounds WA



The Finlay Cup is a Twenty20 match between two teams of Halls Head Cricket Club players. This year the teams were named: *Mazza's Purple Chargers* and *MND Blues*. Each team was supplemented by a number of celebrity players.

Special thanks go to this year's celebrities: Brad Hogg, Ryan Campbell, Aaron Heal, Michael Swart, Paul Haselby, Troy Cook, Daniel Bandy, Bryan Cousins, Craig White

*Sue Colyer*

## Every Australian Counts *a new campaign for the National Disability Insurance Scheme*

You may recall that the National Disability Insurance Scheme was actively promoted during MND Awareness Week in 2010. It is still a project of importance to national MND Australia and supported by the State Associations.

**A National Disability Insurance Scheme (NDIS)** would provide funding for essential care, support, therapy, aids, equipment, home modifications and access to the community, education and training.

It's estimated that only some 3% of the population would be the primary beneficiaries of an NDIS. But all Australians would benefit from the peace of mind of knowing that a Medicare-type safety net was in place, should they or someone they love be affected by disability, either from birth or as the result of accident or illness.

Now you can actively support this new campaign by going to the new NDIS website, looking at the information and signing the on line Count Me In Petition. The time for change has come.

Take action today and make every Australian count.

Count me in: [www.everyaustraliancounts.com.au](http://www.everyaustraliancounts.com.au)  
Take action: [http://everyaustraliancounts.com.au/take\\_action/](http://everyaustraliancounts.com.au/take_action/)



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