



December 2010

In this issue...

Special Features

- ◊ Kerry Coates Memorial Golf Day 2010 1
- ◊ 2010 MND Family Sausage Sizzle 1
- ◊ MND Research Update 6

Regular Features

- ◊ From the EO's desk 1
- ◊ Care Advisors Corner 4
- ◊ Gifts & Donations 7

The office will be closed 24 December 2010 to 5 January 2011 inclusive for the Christmas holiday. See page 4 for after hours contact details.

KERRY COATES MEMORIAL GOLF DAY 2010

Another great day of golf at Glen Iris on Tuesday 26 October 2010. Just over 120 players took part on the day and reinforced to us all that Kerros spirit lives on.

Good to see every one enjoy the day and an Indian food meal afterwards - thanks to Craig for his hospitality. Special mention to Greg "Holiday" Hillman and Harry "Handicapper" Burgess for getting the teams ready to go at 12:30pm.

The winning team comprised of Richard Coates, Chris Lewis, Peter Matera and Chris Anderson playing under the Swan Districts F.C. Banner. There was also a new NAGA winner this year with Cheryl Coates' team doing it easy.

There were lots of prizes given away to the players from our generous sponsors, and several raffles thanks to Michelle Hillman, Cath Anderson, Cheryl Coates and Jan Miller.

Thanks to everyone again for their support for a great day that raised around \$9,000 to help the MNDAWA support people living with MND.



Cliff Anderson

See page 2 for a list of all sponsors.

From the EO's desk

Christmas Party

We all enjoyed good fellowship, good food and good music (courtesy of Minky) at the MNDAWA Christmas Party that was held at the Mt Lawley Golf Club again this year. About 70 guests attended – patients and carers, past carers, volunteers, Board members, sponsors, supporting organisations, and generous benefactors. We thank them all for their participation, support and contribution to the Association over the past year. See page 8 for photos.

This year President Ross Whiteman made several special presentations including:



• President's Award - Honorary Solicitor for MNDAWA, Peter Murray for meritorious service to the association over several years



• Eleanor Mounsher Medal - Karen Brown for outstanding contribution to MND

Continued on page 7

2010 MND Family Sausage Sizzle



Sunday the 21 November 2010, was a lovely sunny day for our Sausage Sizzle with some of our members and their families enjoying the picnic on the South Perth Foreshore.

Thank you to everyone who contributed on the day. A special thank you to Peter and

Parcel for the children, patients and carers. Also thank you to Father Christmas Max who came up from Mandurah, his Elf Reggie and all the Fairies led by Robyn and Dawn.

Thanks to those who donated prizes for the raffle, Barbara & John for attending to the key for me to have the gates opened for the disabled.

To all the Volunteers including my husband Graham who helped on the day, the two lan's who did a wonderful job cooking the sausages and the onions on the day.

Richard Classic Meats, Bakers Delight Kingsley, Julie IGA Kingsley, Ron Food Bank for the lollies, Celia, Pass the

Lois Peck

MND December 2010 to February 2011 Diary

| Date | Event | Time | Venue |
|--|---|----------------|--|
| December | | | |
| Thurs 9 December | Craft Sale | 10am – 2pm | The Niche |
| Fri 10 December | Street Appeal | 7am onwards | Perth Station and surrounding streets |
| Tues 14 December | Carers Christmas Lunch | 11:30am – 1pm | The Niche – Boardroom |
| ** The office will be closed 24 December 2010 to 5 January 2011 inclusive for the Christmas holiday. ** | | | |
| January | | | |
| Thurs 6 January | MND Office re-opens | | |
| Fri 14 January | Halls Head Cricket Club | Starting 5pm | Peelwood Reserve Mandurah |
| Fri 21 January | MNDAWA Volunteers Workshop | 10am – 2:30pm | The Niche – Conference Room |
| Wed 26 January | Australia Day Public Holiday | | |
| Thurs 27 January | Past Carers Barbeque | 12:30pm | Tomato Lake Oak Street Belmont BYO Everything RSVP your attendance to Heather Joppek on (08) 9314 3863 |
| February | | | |
| Thurs 10 February | Craft Group | 9am – 1pm | The Niche – Passmore room |
| Sat 12 February | Helgott Plays The Classics | 6:30pm | Tickets are \$95 per person For more information please call the MND office on (08) 9346 7355 |
| Tues 22 February | Carers Lunch | 11:30am – 1pm | The Niche – Boardroom |
| Thurs 24 February | Pillows and Posture for Fatigue Management Workshop | 10am – 12:30pm | The Niche – Passmore room |

Nifty's December & January highlights...

Carers Christmas Lunch

Tuesday 14 December 2010
11:30am - 1pm
The Niche, Boardroom



Past Carers BBQ

Thursday 27 January 2011
12:30pm
Tomato Lake
Oak Street, Belmont

RSVP your attendance to Heather Joppek
(08) 9314 3863



MNDAWA Volunteers Workshop

Friday 21 January 2011
10am - 2:30pm
The Niche, Conference room

Lunch and refreshments will be provided throughout the day. Please RSVP by 14 January 2011 for catering purposes.

For more information see page 5 of this newsletter or to make a booking, contact Cindy Evans at the MNDAWA office on (08) 9346 7355.



Care Advisor's Corner - December 2010

Christmas is a time to meet up with family and friends, to enjoy each other's company, share meals and exchange gifts. Christmas can also be a time of heightened emotions, particularly with Motor Neurone Disease, as we reflect on the past year's shared happiness, shared sadness, love, loss, achievement and hope. Do be kind to yourself.

Help in the home

One of the difficulties for many people with MND is accepting help in the home. This might be because none of us wants to be a burden on others, or because we feel others are in more need than ourselves. Whilst this can be a very positive approach, it can result in just the opposite. Sometimes a person may experience a rapid change in their situation and if there are no services in place and no pre-planning it can be really difficult to get assistance at short notice. Thus, more stress on families can be inadvertently created.

Holidays

With the warmer weather now upon us, planning for a few days away often starts. If you are using a wheelchair it is important that before you make a booking, you check the accommodation has features which make it accessible. Are the internal and external doorways wide enough? The average width of a manual or powered wheelchair is 65-68cms. If you need large items such as electric beds, shower commodes and hoists, these can often be hired from a local supplier with enough notice. As you would before any holiday, plan ahead and check before you travel to avoid disappointment. A phone call can save a lot of distress, and staff will, generally, accommodate most requests.

Plane travel with a Carer

The Qantas Carer Concession Card is available for a person with a disability who has high level support needs who requires full time assistance of a carer whilst on the plane. A person is eligible if they need to have one on one support when seated on the plane for assistance with meals, drinks, transferring to the bathroom or communicating with the flight staff. The discount applied depends on the fare

class. For more information ask your Care Adviser or contact NICAN (National Information Communication Awareness Network)

Superannuation and Insurance

Most superannuation policies include extra benefits for disability (sometimes known as TPD Total and Permanent Disability or TTD Total and Temporary Disability benefits).

A TPD benefit pays a lump sum if you can't do your usual job or suitable work long term. A TTD benefit pays monthly benefits if you can't do your usual job for now. It's very important to understand how your particular super fund works and what it offers so that you don't put at jeopardy the benefits you may be entitled to.

Maurice Blackburn Lawyers offer a free advice service about superannuation and insurance rights. You can contact them on Freecall 1800 196 050 or via email help@mauriceblackburn.com.au

Dry nose?

Some people find dry nose is a problem, particularly if you're using a VPAP mask. However "Nosoil" can be of assistance. It is a sesame seed based oil moisturiser for the nose that can be bought over the counter at your local pharmacy. As with all medication, it is always wise to talk with a pharmacist to ensure none of the medication you are on will interact with the oil, and is definitely to be avoided if you have an allergy to nuts.

Your Tips

I am endlessly amazed by the resourcefulness with which our people and their families solve everyday challenges. Some of the top tips I've learned recently are shared with you here:

- Pieces cut from an ordinary foam sponge or even some rubber bands wrapped around a pencil/pen can make it easier to grip. A small rubber ball can also be punctured so a pencil can be forced through it to make an excellent grip.
- Large felt tip pens are also much easier to handle than conventional ballpoint pens.

- A small lazy Susan turntable on the desk top for pens, tape, paper clips, etc., can make them easier to reach.
- An electric toothbrush can be significantly easier to use than manual types for those lacking the strength or agility to brush their teeth. Look for one with a rotary brush which is easier to hold in front of your mouth.
- Make a slit and pocket in a thick sponge to hold a flat bar of soap. When showering or bathing just squeeze the sponge to get the suds.

If you have any other tips that have helped you make your everyday living easier, let your Care Advisor know so we can share it with others living with MND.

Wishing you all the best for the Festive Season.

**Cherylyn
Care Advisor**

Holiday and after hours assistance

The MND office will be closed from 24 December 2010 to 5 January 2011. However, the after hours service will be available.

The Care Advisors suggest the following steps if you require assistance over this shut down period. Please use this as a guide.

MND information and advice:

Call the MND 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
- Telephone help line: health direct Australia 1800 022 222

Emergency Respite Needs:

Perth Home Care Services - Crisis Care Service 9244 5411

Emergency Health Care Needs:

Dial "000" and ask for an ambulance

Diana Menzie - MNDWA Emotional Support Advisor



I have been a Care Advisor with MNDWA since 2001. In March 2010 I began a new role within the Care Advisory team. This role focuses on the emotional impact that can occur with a diagnosis of MND.

The most important aspect of my role is listening. The experience of living with MND is different for each person. You will have a team of people who are all concerned for you and who have a specific role to play, making sure you have all the information, equipment and practical support you need. There may be times

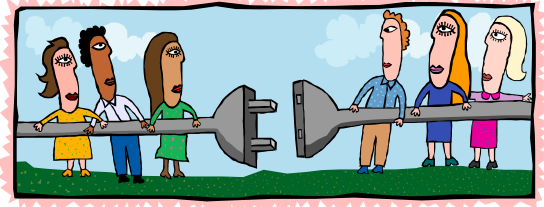
during this experience when your Care Advisor recognises the need for some extra emotional support. This is when they suggest that I become involved.

My role allows for time to be set aside with you to listen and talk about how the experience of living with MND is for you. When the challenge of MND feels overwhelming, it can be helpful to talk with someone whose time is available for listening. I do not have any specific task to carry out while I am visiting you, except for the opportunity to talk.

The Care Advisory Service aims to provide support and information with sensitivity and compassion. It doesn't matter if speech is becoming a problem, we will always find ways for you to have your say.

I look forward to meeting you whenever you and your Care Advisor decides it could be useful.

Diana Menzie
Care Advisor - Extra Support



MNDWA Volunteers Workshop

Friday 21 January 2011

10.30am – 2.30pm

The Niche - Conference room

If you are a volunteer for MNDWA then book out Friday 21 January 2011 for us!

We are inviting all of our volunteers to attend a Volunteers workshop complete with lovely lunch. The workshop will be held at The Niche conference room below the MNDWA office from 10:30am – 2:30pm.

We hope that all volunteers, new and current and past, will be able to attend. The purpose of the day is for our new volunteer coordinator to get to know the people who dedicate their time for us, for you to get to know each other, and to enable volunteers to be a part of the planning and preparation for 2011. Some surprise elements will guarantee you a special fun filled day.

For more information or to make a booking, please contact Cindy Evans on (08) 9346 7355.

MNDWA Volunteer Day is all about giving thanks to worthy people so it is very appropriate to send out a special thank you here to our long time supporter and volunteer Mr John Mounsher. His support enables us to hold these special volunteer gatherings and for that we are truly grateful.

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

Pillows and postures for MND fatigue management

Thursday 24 February 2011

10am – 12:30pm

The Niche, Passmore Room

The symptoms of MND can make it difficult to continue to exercise, and the fatigue associated with MND can make it difficult to want to, but removing exercise from your life is a mistake. Physical activity maintains strength, aerobic capacity, oxygen distribution and blood flow, and it also moves lymphatic fluid. Still lymphatic fluid is a primary cause of fatigue and pain.

On Thursday 24 February MNDWA is holding an information session for people with MND and their primary carers to outline effective habitual movements and postures that can be adopted for fatigue management and pain relief.



Contact Cindy Evans at MNDWA on (08) 9346 7355 for more information.

MND Research Update

MND researchers receive NHMRC funding

MND Australia Research News
15 Nov 2010

Minister for Mental Health and Ageing Mark Butler recently announced \$447.5 million for medical research, through the National Health and Medical Research Council. \$3 million of this funding has been allocated to grants focussing on MND to research groups that include Julie Atkin, Ian Blair, Peter Crouch, Tracey Dickson, Bradley Turner and Justin Yerbury. These researchers have all received grants in aid and/or Bill Gole Fellowships from MNDRIA which has helped them to develop projects that have succeeded in attracting NHMRC funding.

Retrieved from <http://www.mndaust.asn.au/research-news/nhmrc-funding/>

Other links to the latest research newsletters:

Advance MNDRIA – for details of the research projects that have been funded.

http://www.mndaust.asn.au/uploads/30227/ufiles/Advance_December_2010.pdf

MND Australia Research Update

http://www.mndaust.asn.au/uploads/30227/ufiles/MND_Australia_research_update_1210.pdf

Extracts from **MND Australia Research Update 25 November 2010**

Research – Encouraging news, but no cause yet

Over the last 24 months quite an encouraging amount of new information about the causes and contributing factors responsible for motor neurone disease (MND) has been uncovered. However, the cause of most cases of MND still remains a mystery.

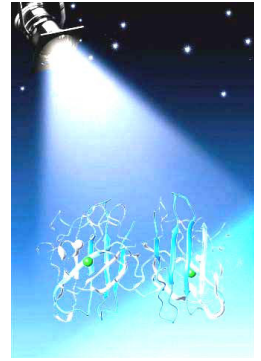
Estimates have frequently placed the number of sporadic MND cases at around 90 percent of all cases (a new report suggests this is not accurate; see *MND Research Shorts*). It is therefore vital to be able to link the inherited, familial forms of MND to the apparently random sporadic cases. Although approximately 20 percent of all familial cases are associated to mutations in a gene called SOD1, recent research shows a group of related genes such as FUS and TDP-43 are associated with familial MND but may also be at least partly responsible for sporadic MND. This casts shadows on the role of SOD1 in MND and its possible importance in sporadic disease.

This is important since most of the potential drugs for MND are tested on mice, and up until very recently the only MND mice carried the human SOD1 mutant. This quarter sees a re-emergence of SOD1 back into the spot light with a report suggesting it may be important in sporadic MND pathology. In

What is SOD1?

SOD1 is the abbreviation for **superoxide dismutase 1**. It is an enzyme that resides in every cell of your body, whose function is to scavenge harmful free radicals. In particular the toxic free radical called superoxide.

The SOD1 enzyme is produced from the instructions encoded in the SOD1 gene. Therefore mistakes, or mutations, in the gene translate to mistakes in the construction of the enzyme. SOD1 can be found present in inclusions in MND affected motor neurones. Inclusions are accumulations of non-functional or damaged proteins (an enzyme is a type of protein). It is thought that the production of these inclusions may play a role in the demise of motor neurones in MND.



Bone marrow transplants a possible treatment for MND?

Researchers in Israel have taken bone marrow from MND patients and injected them back into the same patient's spine. No major adverse effects were reported during follow up.

The patients' symptoms remained stable over the 6 months of study. While it is too early to suggest that using stem cells from one's own bone marrow is a viable treatment for MND, the researchers state that transplantation is a clinically feasible and relatively safe procedure. It is hoped that the cells, once transplanted, may modulate neuroinflammation in the brain and spinal cord.



MND Research Shorts

- *Researchers in Florida, USA* have found that a toxin called BMAA can be found in local animals in levels that could affect human health. Researchers previously attempted to link this toxin to hot spots of MND such as in Guam.
- *Scientists in Ireland* have reanalysed recent data in an attempt to more accurately estimate the number of MND cases that are familial. The researchers estimate the familial versions of MND are more likely to be closer to 5% than the more commonly used estimate of 10% of all cases.
- *The neurotransmitter* best known for creating a feeling of happiness, serotonin, can also be found outside the brain in blood platelets. Researchers in France have shown that people with MND have lower levels of serotonin in their platelets, suggesting serotonin loss may be associated with MND.
- *Researchers in Korea*, have used bee venom to treat MND mice. It appears that in these mice bee venom reduced the inflammation associated with MND and provided a modest



2011 Art Calendar

\$10ea + postage

Call (08) 9346 7355 to
order your copy today!

Proceeds of sale to
MNDAWA.



Gifts and Donations

General Donations

Ms Sue Bolto
Mrs M Berg
Mrs Jan Warhurst
Ms Melany Hall
Hawaii
Mrs Denise Satterley
Dr Sue Colyer
Mrs Maria Lenzo
Ms Corrine Scruby
Mr Ken Gwynne
Mr Solomon Saul
Ms Jennine Ackroyd
Mrs Mary Darvell
Mrs Lorraine Watts

Fundraising

2010 Farm Music Festival
Wembley SUPA IGA
Bunnings Melville
Nancy Martin
Cash & Carry (WA)

Change 4 Change

Mr N Van Der Snoek
Mr Bruce Dawkins

Cornflowers

Newton Moore SHS
Mrs Erla Riley

In Loving Memory of

Sue Franklin-Berner

- Mr Michael Howard
- G & K Ellis
- Nancy Norman
- Christina McDonald
- A Jefferson
- Anonymous

Stephen Brown

- Elba Incorporated
- Upper Swan Primary School
- Ms Judy Griffiths
- Mr & Mrs W & L Schmidt
- Anomymous
- Lamberto Family
- Colleen Reed
- Sharyn Norman
- K J Vigar & Family
- Mr Ron Pass
- Ms Val Fogliani
- Mrs Alison Conroy
- Mr John Mounsher
- Norma Schwind
- Mrs Heather Joppek

Raymon Ettridge

- Mrs Betty Ettridge

Shirley Elliot

- Mr Bob Elliot

John Simpson

- Mrs M E Simpson

Dorothy Piggot

- Mr Noel Piggot

Alan Whitfield

- Mr & Mrs S & B Mangini

Bob Maber

- Mr & Mrs S & B Mangini

Joy Vause

- Mr Kenneth Vause

David Glenister

- Mr & Mrs M & R Levit

Jack Norris

- Mrs Denise Norris

Roger Schultz

- Kelvin & Oana Lord
- Ms Anna Mutty
- Ms Edith Morrall
- Bob & Sue Clark
- Mr & Mrs D & R Cameron
- Berry
- Anonymous

EO's Report - Continued from page 1

- Two new Platinum Partners: Apache Energy and Stadium Snappers for contributing over \$50,000 in the past 10 years
- Crystal Plaques were presented to: Richard and Roma Prince (Bibbulmun Track/Kep Walk), and Banovich Hillman (Kerry Coates Golf Classic)

Congratulations to all our awardees – it is but a small token to acknowledge the wonderful contribution that you have all made directly or indirectly to the people for whom we care. Thank you.

Research

There is some very good news about Australian Government funding for MND research for 2011 (see page 6). The best news is that the amount of money to be spent on MND research has increased to about \$4 million; \$1 million distributed by MND Australia from donations, bequests and small grants, plus \$3 mil from the NHMRC (National Health and Medical Research Council). This additional funding will surely allow the researchers to make progress in understanding the very complex nature of MND.

Overseas travel

While you are all enjoying the warm Christmas and New Year of Western Australia, I will be attending the International Alliance of ALS/MND Associations Allied Professionals Forum and the 21st International Symposium on ALS/MND in Orlando, Florida from 8-13 December 2010. It was a great honour to be asked to present a paper on the *Palliative Care Education for MND Care* that was developed by Curtin University's WA Centre for Cancer and Palliative Care using grant funding. Our Care Advisors were involved in the trials of the program that was very well received by the nurses and hospice carers who took part. Due to the MNDAWA's links with this research centre, we are building a strong relationship for other psychosocial research related to the care of people with MND. The Director of the Centre invited me to represent the Centre (and our Association) at the Symposium at which I will make the presentation on this education project.

This is a wonderful opportunity to meet with international colleagues and to hear the latest in medical and other research that focuses on MND. Other Australian colleagues, from Melbourne and Sydney, will also be attending, so there will be a sizeable contingent going from Australia this year. Next year the 22nd Symposium is to be held in Sydney.

After the meetings in Orlando, I will take advantage of being in the USA to visit some friends in the northwest State of Washington, and also to travel to New York for Christmas and New Year. I look forward to telling you all about the latest international news on MND in January.

May you all have a safe and peaceful Christmas and enjoy the fun of the New Year with family and friends.

Dr Sue Colyer
Executive Officer

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



www.mndcare.net.au

Helping People Living
with Motor Neurone
Disease to Live Better
for Longer

From everyone at MNDAWA

Merry Christmas



Image: Simon Howden / FreeDigitalPhotos.net



Thanks to our newsletter sponsors



Ray White

Devon Settlements
Independent Settlement Agency



Support the companies that support us



If you no longer wish to receive MNDAWA Newsletters or if you would prefer your newsletter by email, please contact us via phone (08) 9346 7355 or email admin@mndawa.asn.au



Thank you for helping us conserve our resources.