

November 2010

Blue on Blue Art Exhibition

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By the time you are reading this newsletter the Blue on Blue Art and Photography Exhibition will be concluded. This fundraising and awareness raising project was a trial to bring together two artists from different backgrounds and artistic talents, yet with such a similar philosophy towards nature and the environment. Carilley Estate Vineyard was the venue, as it has been for many of our recent events, especially

the Global Day luncheon. We are fast building a relationship with Carilley to our mutual benefit, thanks to Wayne and his team. Here is a photo of Karen Brown and Ann Land at the end of a busy day setting up the exhibition last week.

As part of the fundraising activities, we produced a calendar of Ann's images. The calendar is for sale at the MNDAWA office or by postal order. The calendar costs \$10.00 and

all proceeds come to the association. We thank the printers, We Print It, who especially prepared this calendar and sponsored it for us to keep production costs low. Thank you to Alex and Greg Coulson.



Opening night photos on the back page.



South West Visits



We have about 25% of our patient members living outside the metropolitan area and due to limited resources in the past, reaching out to those members has been difficult. These members likewise find it difficult to travel to the city for appointments, information and support sessions, and to access other resources located in the metropolitan area. We are dependent on the services that exist in those areas and in particular on the Regional Neurological Nurses who are employed by NCWA. Our rural clients are dependant on their



local health and disability services, as well as the local community to provide the support and equipment that we cannot.

This year the Board encouraged visits by Board members and staff to Albany, Geraldton and most recently Bridgetown and Northcliffe. The last weekend in October, Care Advisor Samantha Whittle and I travelled to Bridgetown and Northcliffe to visit clients. We received very warm welcomes. We were able to provide information and support, and to acknowledge in Northcliffe the caring community support and fundraising efforts. Here are a couple of photos from that visit – Samantha with John and Jenny with friend at the Bannister Downs Dairy, and Jenny at a High Tea event in Ken and Kay's lovely garden that raised money for MND research.



Sam and I were overwhelmed with the generous hospitality and we thank our hosts for the very warm reception.

Sue Colyer

From the EO's desk

October was another month full of events for us at MNDAWA. I attended part of the round table meeting of CEOs of organisations in the disability sector that was hosted by Disability Services Commission and it was interesting to note the common issues that we all face particularly with the complexity of funding

models, as well as similar operational issues. The Care Advisors were involved in a professional training workshop, as well as running the MND DNA Bank session and the seminar for people newly diagnosed with MND. I commend all the Advisors, Cindy, Diana, Sam, Rose and Cherylyn, and our volunteers for the way in which they managed a very busy and emotional day. And I thank Dr Rob Edis for his presentation at the seminar, which was

presented most sensitively and professionally. These two programs were scheduled for the day of Stephen Brown's funeral, and it was appropriate that the day's activities continued, as a tribute to Stephen's legacy.

We all share the grief of the passing of Stephen Brown. Stephen was an inspirational man with a passion for the care of people with MND, and for research

Continued on page 2

MND November 2010 to January 2011 Diary

Date	Event	Time	Venue
November			
Sun 21 November	Family Christmas Sausage Sizzle	11am – 3pm	Sir James Mitchell Park Clydesdale Park - South Perth Douglas Avenue, just off Coode Street
Tuesday 23 November	Carers Lunch	11:30am – 1pm	The Niche – Volunteers room
Thursday 25 November	Past Carers Group	4pm	479A Lebnard Street, Dianella RSVP your attendance to Sheila Nicholson on (08) 9275 0708 by 24 November
December			
Wed 1 December	Christmas Cocktails	6 – 8pm	Mount Lawley Golf Club
Thurs 2 December	Volunteers Meeting	10:30am – 12pm	The Niche – First Floor Room
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	TBA	TBA
** The office will be closed 24 December 2010 to 5 January 2011 inclusive for the Christmas holiday. **			
January			
Fri 14 January	Halls Head Cricket Club	Starting 5pm	Peelwood Reserve Mandurah
Fri 21 January	MNDAWA Volunteer Workshop	10am – 2pm	The Niche – Conference Room

Nifty's November highlights...

Carers' Lunch

Tuesday 23 November 2010

11:30am - 1pm

The Niche Volunteers Room

Free 2 hour parking available at The Niche. Light snacks and refreshments provided.



CHRISTMAS FAMILY PICNIC GET TOGETHER

Sausage Sizzle with Santa, his elves and fairies

Sunday 21 November 2010

11am to 3pm

Sir James Mitchell Park -
Clydesdale Park South Perth
(Turn off Millpoint Road at Coode Street lights)

Disabled toilets available, gates will be open for vehicles to drop off partygoers.

\$3 per person or \$10 for a family of four

There will be plenty to eat, BYO drinks – Alcoholic if you wish. Please BYO chairs and picnic rugs

DAY RAFFLE WITH PRIZES

If you have any queries please phone Lois on (08) 9409 6076 or the MND office on (08) 9346 7355

HOPE TO SEE YOU THERE!!

Volunteers Needed

Are you available

Friday 10 December 2010?

The MND Street Appeal is on again this year and we need your help to raise funds for MND.

The main base will be at the Perth Station, Seniors Room. Collection cups can be picked up from there on the day or from the office prior to the Street Appeal day.

If you would like to help or have any further queries, please contact Lois on (08) 9409 6076 or the MND Office on (08) 9346 7355.

MNDAWA Volunteer Day

Friday 21st January, 2011

10.30am – 2.30pm

*more information to be provided in the December newsletter



Managing Fatigue – Managing Stress – Good Sleep

It is getting near to Christmas, the temperature is rising and no matter what else is happening, the pace of life seems to quicken. This is the perfect environment for fatigue, stress and lack of quality sleep. However, there are ways to lessen the impact these symptoms have on your everyday life. To be aware and take some simple precautions can make a world of difference to your wellbeing. You need to be aware of some of the common factors and symptoms that overcome those with MND as fatigue, increased stress levels and a lack of good quality sleep can be of concern for both the diagnosed member and for the primary carer.

Fatigue and ways to manage

Fatigue that accompanies neuromuscular damage is very real. This type of fatigue can occur suddenly, last a lot longer and can take much longer to recover. It may be the result of any mild exertion or physical activity. Mental activities undertaken in the daily course of your day can also cause fatigue and simple tasks such as reading or talking can increase the effects of fatigue.

Some symptoms of fatigue are:

- Slowness in your movement and speech, quieter voice, husky voice tone
- Shortness of breath, loss of appetite, loss of personal interest in normal tasks
- Increased anxiety, emotional liability, or you may become withdrawn from life

Strategies for Managing Fatigue

Fatigue can be managed when these symptoms are recognised. A planned rest period in daily events can make a difference to the quality of life.

- Plan activities, rest periods and the combination of distance and length of outings or activities.
- Discuss with your physiotherapist exercise routines that are safe and beneficial.
- Be aware of heavy tasks and the energy required, plan shortcuts to achieve the same result.
- Use mechanical aids when possible

and make sure your environment is safe and easy to get around.

For more information on fatigue and managing these symptoms, please visit www.mndacare.net.au and read the Motor neurone Disease More Facts / Fact Sheets for Carers.

Coping With Stress

Stress is a normal body reaction when it is put under extra strain. We all encounter stress in our normal daily lives, which can lead to emotional and physical strain. Carers are prone to stress and feelings of being overwhelmed with the demands of the ongoing 24 hour care of their love one. It is hard work for all and needs to be recognised as real.

Symptoms of Stress

- Increased heart rate, blood pressure and breathing
- Irritability and a feeling of being unable to cope, or over active
- Feelings of not being understood, thinking becomes likened to being in a fog
- Decreased immune system, difficulty in sleeping

Tips for managing stress

Share how you feel and release any feelings of guilt you may be encountering.

Talk it through with your Care Advisor, GP or a valued friend.

Get some counselling - can be obtained through different paths. Ask your Care Advisor.

Consider joining a Carers Support group.

Caring for a loved one can stretch family relationships due to the various pressures on a family. Although most of these pressures would not normally be there, they can bring closeness and encourage displays of love and family support. Talking about what is happening to you and sharing information can bring support and relief from many different areas sometimes even from an unexpected source.

www.mndcare.net or Care Advisory Emotional Support Service.

Sleep Difficulties

Sleep difficulties can start for various reasons such as discomfort, pain or

either excessive saliva or a mouth that is too dry. Respiratory and sleep problems are assessed by the Respiratory/Sleep Disorder Clinic at Sir Charles Gairdner Hospital - some non-invasive breathing assistance may be just the answer.

Sleep Strategies

Reposition the bed regularly - use satin or silk sheet to assist movement.

Use special overlay mattresses to even out the pressure of body weight.

An electric bed with side rails can assist with turning and safety, and also with breathing and saliva management by elevating head of bed.

Ask your pharmacist or GP for non-prescription analgesic or medication.

Consult a physiotherapist for a range of motion exercises that can assist with good sleep.

A slow rhythmic back rub or massage can relieve muscle pain and aid sleep.

A darkened room, that is either quiet or with soft music, can promote good sleep.

Difficulty sleeping can be experienced by receiving the diagnosis of MND and trying to live as normal a life with loved ones. There are people to assist in coping. These people are your neurologist, your GP and your Care Advisor.

*Rose Gibbins
Care Advisor*

Dates to Remember

Carers Lunch - 23 November 2010

Guest speaker: Barbara Stubber - The Homelink Respiratory Nurse



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

www.mndcare.net.au

A 'one-stop shop' website that provides access to latest evidence based and best practice MND symptom management and support information.

Members' Survey Report

In June 2010, all members of the MND Association of Western Australia were invited to complete a questionnaire. The Board was interested to have the views of members on a number of matters, such as, level and type of services, and future directions for the Association, as well as specific opinions on investment strategies and respite. This report is an abridged version of the key responses to give a picture of the views of members and their perceptions and expectations of the Association.

Two hundred and thirty questionnaires were mailed to members listed on the data base. Sixty three forms were completed and returned, representing a response rate of 27%, which while appearing low is within the acceptable range for mailed surveys. It is also accepted as sufficient given the make-up of our membership.

Reasons for joining MNDAWA

These was a long list of reasons for joining the Association, but on closer analysis, of the 95 reasons listed, 86 (90%) were care related: carers, family members, and patients who look to the Association for assistance and to be with others in a similar situation. There is also a relatively high number of responses from people who joined to support the Association (16 or approx. 16%).

Five (5) top priorities for MNDAWA in the next three (3) years

These responses are shown in Table 1 below to reveal that the top five priorities for the Board in the next three years as perceived by the members are *promoting research, providing information and education and maintaining the equipment service, advocating, referrals*. More than half the respondents listed the first three issues as their top priorities. These responses will assist the Board in its strategic planning early in 2011.

Table 1. MNDAWA Priorities for the Next 3 Years – 2011-2013

n.	%	Priority
42	13.6	1. Promoting research
40	12.8	2. Offering information and education to people with MND and their families
33	10.6	3. Maintaining an equipment service
23	7.4	4. Advocating and influencing funding agencies for support for people with MND
22	7.0	5. Providing referrals for patients to other services

Satisfaction with MNDAWA services used

There were 41 complex comments about the members' experiences of our services, and generally the responses were positive about the level of service, amount of information available and the personal support from the activities, such as the newsletter and supporting functions. The following table shows these responses relating to *equipment, interventions, support groups* and overall *general satisfaction*.

Table 2. Services used and Satisfaction with MNDAWA services

Issue	Statement
Equipment	Need for more information on equipment funding Need for more information on maintenance of equipment
Interventions	Earlier advice on interventions, especially PEG for better nutrition
Support Groups	Benefits from Pamper Day and newsletter Carer support group
Satisfaction	Services, including newsletter Care Advisors Friendships

Not satisfied with MND services

Responses from six members contained seven issues and it appears that

the aspects of dissatisfaction relate to some direct and some indirect areas of influence for the Association.

Research, the manner and experience of GPs and Neurologists are beyond the Association's direct influence. However, the other issues, such as *frequency of Care Advisor visits* can be investigated and reviewed, as can the experience of those who support the *pamper days*. Other direct activities include *raising funds and awareness* in the Western Australian community to support our services and to forward some funds to MNDRIA to support research. It appears that there is low dissatisfaction with the direct services of MNDAWA.

Importance of MNDAWA services to members

Members were asked to think about 19 MNDAWA services that they have used or knew of and to rate them on a 5-point scale of *Not Important* to *Very Important*. Their responses are shown in Table 3 below.

The top five (5) important services ranked by mean (average) score are: *newsletter, information, equipment, trained staff* and *respite*. Generally, there is very strong statistical agreement with these rankings.

Table 3. What is Important to Members

Rank	Services/Activities	Mean	SD
1.	MND Newsletter Print and Electronic	4.7	0.5
2.	Written information about MND,	4.6	0.8
3.	Equipment	4.6	0.8
4.	Trained staff to visit you at home/work	4.5	1.4
5.	Respite	4.5	1.0
6.	Information and updates about research	4.4	1.1
7.	Opportunities to participate in research	4.4	0.8
8.	Information sessions for families/workers	4.3	0.9
9.	Carer information meetings	4.2	1.1
10.	Fundraising events	4.2	1.0
11.	Awareness activities	4.2	1.0
12.	Phone based information service five days a week	4	1.1
13.	Patient and Carer get-togethers	3.9	1.2
14.	MNDA WA website	3.8	1.1
15.	Social activities	3.7	1.1
16.	MND specific merchandise	3.6	1.3
17.	After hours phone service	3.4	1.5
18.	Opportunities to meet MNDAWA Board/CEO	3.3	1.2
19.	Past Carers meetings and activities	3.2	1.1

Summary and conclusions

Again only the main areas are presented here, as the Board will need to consider the actions that are suggested in the full report. A detailed copy of the report of the results of the members' survey will be placed on the web page once it has been reviewed by the Board.

The findings from this survey are grouped as follows:

1. Practical ideas to improve direct service delivery to MND patients and carers
2. Service areas to maintain and strengthen
3. Service aspects to improve
4. Future directions.

Direct service delivery suggestions

Distilled from all the comments and responses, two main areas related to direct service deliver were:

- Care Advisors
- Support Groups

Maintaining and strengthen current services

Many comments suggested improvements or offered a perspective on the benefits of current services. The actions suggested build on current activities to extend our capacity to support our clients.

The response to our DNA Blood Bank day is an indication of the interest that our members have in research, so it is timely that the latest round of research funding for 2011 MND research projects was announced last week. Carol Birks the National Executive Officer of MND Australia advised us that almost \$1.4 million was awarded for research grants in 2011 at the Grants allocation Meeting last week. Carol said, *“This is more than double the amount that was awarded for projects in 2010 and about ten times the amount that was awarded six years ago”*.

Carol also reported that the *“Research Committee members were all amazed at the amount available and recognize that research funding allocated through MNDRIA over the years is really driving MND research in Australia”*.

You can see the scope of the fifteen projects to be undertaken, including two by Western Australian researchers. We congratulate these Western Australian researchers on their success in receiving funding for MND research.

Dr Rachael Duff at the Western Australian Institute for Medical Research received funding for her project on *“The application of new generation genetic techniques to motor neuron disease”*. Another grant was received by Dr Moira O’Connor, Curtin University WA, for her children’s pilot study titled: *The experiences and psychosocial needs of children 11-16 years of age who have a parent living with MND*. MNDAWA is supporting this grant funded project and will be involved in working with the researchers as the project develops. MNDAWA has a strong link with Curtin University’s WA Centre for Cancer and Palliative Care, at which the researchers have a strong interest in social MND research, and Dr O’Connor’s project is the only social research project funded by MNDRIA.

There were 13 other projects granted funding for areas such as drugs, monitoring disease progression, stem cell therapy, breathing therapy, and cognition and behaviour.

The research donations that are received by us are forwarded to MND Research Institute of Australia (MNDRIA) and go into the pool of funds that is distributed annually in response to the applications from researchers at various universities and research centres across Australia. Some of your past donations will be contributing to these projects in 2011.

MNDRIA Grants commencing in January 2011

Investigating the cause of site-specific excitotoxicity in ALS

The application of new generation genetic techniques to motor neuron disease

Novel therapeutic agents for motor neuron disease with optimal pharmacokinetic properties

Identifying who will benefit from Non Invasive Ventilation in Motor Neurone Disease in a clinical cohort

Using next-generation DNA sequencing strategies to identify new MND genes

Comprehensive assessment of MND patients as a means to studying progression and identifying disease subtypes

Motor neurone disease fluid and brain bank for scientific research

The role of the innate immune system during the progression of MND: the search for new therapeutic targets.

Children’s pilot study: The experiences and psychosocial needs of children 11-16 years of age who have a parent living with MND

Looking for de novo mutations in sporadic ALS using trios and nextgeneration sequencing

Targeted down regulation of SOD1G93A in MND mice

Development of a stem cell therapy for motor neuron disease

Are endosomal transport defects a primary cause of MND?

Identifying genes that are regulated by TDP-43 and FUS using highthroughput sequencing

Does TDP-43 aggregation cause translation arrest in motor neurons?

Recently Diagnosed Seminar

Thursday 28 October MNDAWA held a seminar for people who had recently been diagnosed with MND. Nearly 30 people attended on the day to listen to talks from the manager of the MND DNA Bank in Sydney Lorel Adams, Neurologist Dr Robert Edis, MND Care Advisor Samantha Whittle, and Service Support Advisor Cindy Evans.

People who attended on the day were led through the intricacies of MND by the medical specialists, introduced to the staff at MNDAWA in a lovely informal setting, and provided with information and contacts that will make managing and planning the course of their disease easier. Feedback given on the day suggests that it was a valuable and informative seminar and that it should be held regularly. Another seminar is being planned for next year.

Many thanks to all who attended and we hope to hear from you often.

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General Donations

Yuluma Primary School	Abigail and Andrew Armstrong
Mrs Lorraine Reed	Ms Dawn Hillman
BHP Billiton Matched Giving Program	Mr Ken Pitts
Mrs Beryl Barclay	Mr Michael Young
Mr Bruce M Johnson	E Hunter
Rotary Club of Como Inc.	Barry and Jan Ingram
Dr Robert H Wittenoom	Mr Robin Ottewell
Mrs Elsa Wilkins	L R Thomas and family
Mr James Ferguson	Mr Trever Mark Fry
Mrs M Berg	Mr R Burvill
Dr Sue Colyer	Mrs Christine Bramwell
Ray White - Urban Springs	Janeen Kerkhofs
Ms Jo Woodfield	The Hon. David K Malcolm
Ms Melany Hall	SOCS Manjimup Football Team
Jeanne Black	Mr Ian Clarke
Steve and Marian	Telstra
Ms Nola Selfe	Northcliffe Workers Club Inc
Ms Kate Lawrie	Ms Val De Burgh
Wendy and Ronnie	Mr Bruce Nicholls
Dr J Baker	Mr George Sheed

In Loving Memory of

<i>Geraldine Manley</i>	<i>Bruce Veitch</i>
- Croma Coatings	- Ms Barbara Twells
<i>Frank Bussell</i>	- Mr and Mrs R Powell
- Mrs Betty Bussell	- Dr and Mrs R Freer-Hewish
<i>Sue Franklin-Berner</i>	- Mr and Mrs R Elliot
- Mrs L Lorian	- Department of Environment & Conservation Exmouth
<i>Michael Dilley</i>	- Mr and Mrs M Boisvert
- Ms Barbara Twells	- Mr and Mrs D Haworth
- Mr and Mrs R Powell	<i>Stephen Brown</i>
- Dr and Mrs R Freer-Hewish	- Ms Ling Lee
- Mr and Mrs R Elliot	- Mrs Erla Riley
- Department of Environment & Conservation Exmouth	- Mr Don Quelch
- Mr and Mrs M Boisvert	- Ms Val De Burgh
- Mr and Mrs D Haworth	- Ms Margaret Sealey

Cornflowers

Greg and Mary Downs
Bunnings Melville

Fundraising

Fremantle Public Golf Course
Whaleback Ladies Golf Club

Change 4 Change

Kym Chambers
Ms Leila MacNish
Mrs Gwen Wiley

Bequests: 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

Fundraise Online

MNDAWA is now registered with everyday hero so you can donate and fundraise for MND.

For more information about fundraising and becoming an everyday hero for MND, please visit www.everydayhero.com.au



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Members' Survey Report

These areas of focus are:

Things to improve

- Membership
- Education/information
- Emotional Support
- Professional alliances
- Volunteers
- Equipment
- Carer Training
- Awareness
- Newsletter

There are two issues for improvement:

- Respite
- Travel

Future planning

While all of the priority options provided in the questionnaire were rated highly by the respondents, the top seven are those that draw attention and give a direction for Board strategic planning and operations for the next three years. The priorities that attracted 10 or more responses are listed below. These priorities will focus future planning deliberations of the Board at the review of the strategic plan:

- Promoting research
- Offering information and education to people with MND and their families
- Maintaining an equipment service

- Advocating and influencing funding agencies for support for people with MND
- Providing referrals for patients to other services
- Providing respite
- Attempting to influence government policy

Conclusion

This member survey produced some interesting results that on one hand endorse the activities and the services of the Association, while on the other hand offer some directions for the future, and some practical suggestions to improve the service we currently provide. These results evaluate our past performance and offer some signposts for the future planning.

In closing this report, I thank all the members who took the time to give us their considered views on the services that we provide and for highlighting those issues that are important to them. The Board can move forward knowing that it has an indication from members of their needs and the types of actions that they believe are necessary to strengthen and improve our services in order to support our members living with MND.

Sue Colyer
October 2010

Blue on Blue Art Exhibition Opening Night



2011 Art Calendar

\$10ea + postage

Call (08) 9346 7355 to

order your copy today!

Proceeds of sale to

MNDAWA



Stephen Brown - An inspirational life

Stephen Brown will be greatly missed by all of us associated with MND in Western Australia, for he had a cheeky sense of humour, a determined spirit to improve the care and research for MND, and a charm that few could resist. The MND Association that we have today in WA and Australia is largely due to the early and continuing efforts of Steve.



Stephen and wife, Karen Brown.

Stephen Brown was a long time leader in our Association. Steve was President of the West Australian Association for several years, and served on the Board from 1992 until retiring at the AGM in Oct 2010. He attended the first ever National MNDA Australia Conference and also served as National President for a number of years. He attended the International Conference in France in 1993, where he spoke and challenged the international scientific community 'to get cracking' with their research - for his family's sake.

He organised numerous fund raising events, dinners and medical conferences, and he was a driving force behind patient get-togethers and social events. Steve even organised this year's Global Day lunch for patients and carer from his electric wheelchair, when by this stage he could not walk, use his arms or speak, and was breathing with the help of a Vpap machine. He did it all via email with special software on his computer.

In 2001, he wrote a 240 page resource manual, titled MND Scrapbook, for people living with Motor Neurone Disease and health professionals, as there was no information available when he was diagnosed. This took him 18 months to complete as again he could not use his hands by this stage and had to use special software on his computer to type. There is a copy in the Batty Library, and the WA MND Association can provide copies.

Stephen Brown is described as a crusader and a warrior for people living with MND. With no time to waste, Steve was direct in his demand for research to find a cause and cure, and for the services to provide the care. It was a cause that he pursued for nearly 23 years following his diagnosis.

The sum total of a man is not only what he achieved, but it is who he was - a hero and icon for people dealing with the diagnosis of MND; a man of high integrity, honesty and intelligence. But most of all Steve was a family man who dearly loved his wife and sons.

Our sincere condolences, thoughts and prayers reach out to support Karen, Michael and Mathew at this time of great sadness.

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