



FORUM

Day of Hope and Remembrance 6 May 2009

“The lighting of this candle honours you and reflects the hope we share for research to find effective treatments and the triumphant cure for motor neurone disease.”

Pamela Hennessy

During MND Week, MND NSW held a Day of Hope and Remembrance at the Soka Gakkai International Centre, Sydney Olympic Park. Over 130 people from the MND community joined together to celebrate hope while also remembering those who have died from motor neurone disease.



Marcia Bond lighting the candle for families and friends of people living with MND (above) and Ben Cheah representing MND researchers (below).



Our guest speaker, Professor Dominic Rowe, spoke of hope and MND research. His personal account of the loss of a friend to MND brought home the impact MND has on all of us.

During the Dedication and Candle Lighting Ceremony nine small candles were lit from a larger MND candle as a personal dedication was read by a person representing one part of our MND community. Members, past and present carers, volunteers, health and community professionals, researchers, MND NSW board, staff and those involved in the global efforts towards a world free of MND were all represented. The ceremonial part of the day concluded with one minute of silent contemplation.

The day also provided a great opportunity to acknowledge several of our volunteers with life membership awards. Phil Bower, President of MND NSW and Graham Opie, CEO of MND NSW, presented these volunteers with certificates and a special badge to honour their continued efforts. Afterwards, people had the opportunity to mingle, chat and share experiences over afternoon tea.

It was the first of what is hoped to become an annual event. Thank you to those who helped to make this a special day.

“This candle... is shining for all our volunteers and supporters who, cheerfully and generously, give time, effort and monetary donations to support and participate in activities such as raising awareness, fundraising, office work, advocacy and research.”

*Marjorie Harrap,
Founder and Life Member
MND NSW*

“This candle is being lit in honour of those involved in support groups for people with MND. For the acceptance; the emotional and practical help and support in facing the many challenges; the sharing of knowledge and care for group members. For the fun and nonsense shared by the group members which helps make the journey that little bit easier and to honour every person who has contributed to a support group.”
Lesley Brennan, dedicating a candle from those involved in MND support groups.

“We light this candle in memory of the courageous, inspirational spirit each of us has loved and lost to MND.”

Justine Wallis reading a dedication by Lesley Brennan, from those involved in MND support groups.

“... today I want to focus... on sending out a cry to those who are not living with MND - but who have access to the power and resources which can improve the quality of our lives and, especially, hasten the quest for an eventual cure. I refer to governments, research bodies, philanthropists, and any other organisations and individuals with the power and resources to help us, the “we”. ”
Paul Brock AM, Vice-patron MND NSW, in his dedication from those involved in the global fight against MND.



MND NSW President, Phil Bower (back right), with life members (L-R) Val Retalic, Audree Dash, Kevin Langdon OAM, Sheila Holmes and Marjorie Harrap,



Talented musician, Helen Park, who performed on piano and flute on the day.

Motor neurone disease is known as amyotrophic lateral sclerosis (ALS) or Lou Gehrig's disease in some countries. The Blue Cornflower has been adopted in most countries as the symbol of hope for people living with motor neurone disease.

More from the Day of Hope and Remembrance

Meryl Hanford with the banner featuring the photograph of her late husband, Paul Hanford



Pamela Hennessy with Paul Brock AM



Carol and Kathryn Hicks



Sisters, Vanessa MacArthur and Fiona Thomas with the banner featuring the photograph of their dad, Glyn Stark with their mum, Beth Stark



Chris Lambert, Jill Lambert, Maureen Blissett, Brooke Walker and Kate Walker



(Clockwise from L) Courtney Borg, Emily Puckeridge, Cathy Turner and Coral Thoroughgood



Sandra and Paul Tosolini (above) and Cynthia Greentree (below)



(L-R back row) Ron, Justine and Keith Wallis, Wal Preston with (front row) Liam Wallis, Darryl Preston and Rosanna Wallis in front of the banner featuring the photograph of Ron's late wife, Amy Wallis



Thomas and Jue Gardner (above) and Alexander and Liz Sandwith with Gwen Anne Taggart (below)



The MND NSW Centre at Gladesville will be **closed** on **Tuesday 23 June 2009**. Staff will be attending the 5th National MND Conference.

Link and Learn

An educational, support and self-care program for rural and regional MND Carers

30-31 July 2009

Ballina Beach Resort, Ballina NSW

Link and Learn provides education in caring for people with MND as well as offering support and self-care activities. This MND NSW program is provided free-of-charge for MND carers in this region and includes an overnight stay at Ballina Beach Resort.

Carers living in or near the far north coast of NSW will receive more details by 30 June. However, if you would like to know more now, contact Robyn Peterson or Gina Svolos ph. 8877 0999 or 1800 777 175 or email ginas@mndnsw.asn

Funded by NSW Department of Ageing, Disability and Home Care

Ask the Experts Forum and MND DNA Bank Donor Drive

Monday 17 August 2009

West Ryde NSW

Ask the Experts is an opportunity for members, their families and their carers to ask questions about motor neurone disease.

Lunch, tea, coffee and on-site parking are provided.

You must RSVP by Friday 7 August to attend this event. For more information see enclosed flyer or contact MND NSW ph. 8877 0999 or 1800 777 175.

Join the Australian MND DNA Bank Donor Drive when you come to Ask the Experts.

If you wish to be a donor on Monday 17 August bookings are essential.

See enclosed flyer for more information.

A Message from the CEO

MND Week 2009 was an outstanding success. Train stations, airports, shopping malls, and even the NSW Parliament, were awash with blue cornflowers, MND information and merchandise. Thank you to the volunteers, members supporters and staff of MND NSW for your efforts. Media interest in MND is growing and the efforts of MND Australia in coordinating our national MND Week media campaign this year are to be commended.

During MND Week we held our inaugural Day of Hope and Remembrance at the Soka Gakkai International Centre, Sydney Olympic Park. I enjoyed catching up with many of our members there and congratulate Audree Dash, Marjorie Harrap, Sheila Holmes, Kevin Langdon and Val Retalic on the presentation of their special MND NSW Life Member pins.

Just after MND Week, a new Australian DVD about one family's experience of living with MND was launched. *Glass Half Full* has been a collaborative effort between Karuna Hospice in Brisbane, an independent producer and MND Australia, and special thanks have to go to the Hynes family who appear in the film.

As I write this piece it is only one month to MND Global Day. This year, in conjunction with MND Australia, we will be holding a Walk to d'Feet MND

around Lake Burley-Griffin on Sunday 21 June (see page 9). On Monday 22 June a meeting in Sydney of family support workers from MND associations across Australia and New Zealand will precede the 5th National MND Conference for health and community care workers. These annual meetings have proved invaluable in raising the levels of expertise and knowledge of people working with those living with MND, their families and carers.

On conferences, a special mention needs to be made of our regional advisor, Jo Fowler. Jo will be presenting a paper at the National MND Conference on a joint MND NSW and Home Hospice initiative she has coordinated. Her paper has also been accepted for the National Palliative Care Conference to be held in Perth during September and has been submitted for the 20th International Symposium on ALS/MND and Allied Health Professionals Forum to be held in Berlin, Germany in December.

To all those who have lost loved ones and friends to MND I extend, on behalf of the Board and Staff, our deepest sympathy.

Graham Opie
Chief Executive Officer

If you would like to receive Forum by email let Petra know by emailing your name, address and email address to admin@mndnsw.asn.au.

You may have noticed several changes to the format and style of the newsletter, Forum. The major costs involved in producing Forum are printing and mailing. We have now updated the design so the newsletter is easy to read in both print and web formats. By notifying us of your willingness to have Forum emailed to you we can reduce our print-run and dramatically decrease production and mailing costs. The email and web versions of Forum are produced in colour throughout.

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And..... many valued volunteers


 PARLIAMENT OF NEW SOUTH WALES

Home Hansard & Papers Legislative Assembly
5 May 2009

Speakers - O'Dea Mr Jonathan

MOTOR NEURONE DISEASE

Mr JONATHAN O'DEA (Davidson) [1.37 p.m.]:
Motor neurone disease, known as MND, affects various people in my electorate, including Mr Phil Brady. Motor neurone disease is the name given to a group of diseases where there is a failure of normal functioning of the nerve cells controlling the muscles that enable us to move around, speak, breathe and swallow. With no nerves to activate them, muscles gradually weaken and waste. In Australia, about 1,300 people have the disease. There is no definitive cause and it does not discriminate on the basis of sex, race or age. There is no cure. From the time of diagnosis, the average life expectancy is 27 months. In 2006, 532 Australians died from the disease. Although we know there are high-profile people with MND, such as Professor Stephen Hawking, few people have a good understanding of it and its impact on everyday life.

Motor neurone disease is an extremely cruel disease. What may start as weakness in the hands or feet, a swallowing difficulty, slurred speech or muscle twitching and cramps, eventually develops into paralysis. Patients eventually become completely immobilised and are only able to move their eyes on their own. MND affects people differently, although progression of the disease is generally rapid. This means that those diagnosed, their family, and their friends are forced to adjust quickly to a very difficult and stressful situation. Performing basic functions, such as walking, breathing, eating, dressing, showering, and going to the toilet, become serious challenges. This situation has a massive psychological effect, as once independent people become dependant on others. It also has a large impact on carers, who make enormous sacrifices. Despite massive physical limitations, those with motor neurone disease do not usually suffer any intellectual impairment, and can still make substantial contributions to society. Consider the impact of Professor Stephen Hawking.

Mr Phil Brady of St Ives is a retired certified practising accountant and has been living with motor neurone disease for 14 years. In 1995 Mr Brady was a busy accountant when he noticed problems using his hands and began getting cramps. He was later diagnosed with motor neurone disease by a neurologist, but calls himself lucky as he has a form of the disease that progresses more slowly than most. Yet, simple tasks such as swallowing prove difficult. Despite his physical limitations Phil remains active in the

broader community. Phil uses his accounting and financial expertise to help non-profit organisations such as the Motor Neurone Disease Association of New South Wales, led by chief executive officer Mr Graham Opie. In addition, Phil raises awareness about the disease, and did so with me. I applaud Mr Brady for his remarkable resilience, commitment and perseverance. I also acknowledge his wife, Trish, who provides him with constant care, with support from their children Karen, Megan, Louise and Phillip.

Despite the resourcefulness of those with motor neurone disease, government support is essential. Looking after the most vulnerable in society is a key government responsibility, and support should be individually tailored to patient needs. Currently those diagnosed under 65 years of age are able to access disability services from State governments, while those diagnosed when aged over 64 years generally access residential care facilities provided by the Commonwealth Government. This is a problem because some people under the age of 65 require residential aged care facilities while some over 64 really need State-based disability services. This Federal-State responsibility dysfunction must be better resolved through the Council of Australian Governments process.

Governments must tailor services not only to the disease but also to individual circumstances. Motor Neurone Disease Australia has devised a summary of needs, which includes: early diagnosis given by a neurologist expert in the disease; counselling and support at and following diagnosis; early access to motor neurone disease associations for information, support and referral to services; accurate information; timely access to specialists; equipment to maintain independence and quality of life; flexible and timely respite for carers; and personal home care and support. Despite the existence of common needs, governments need to be flexible and responsive to individual needs, as the disease affects people differently.

It would be wonderful if motor neurone disease received greater attention and governments mirrored the commitment of motor neurone disease organisations in New South Wales and around Australia. This week is Motor Neurone Disease Week. The aim of the week is to raise awareness and funds for the disease. Tomorrow is the special day of remembrance and I will be distributing lapel badges with blue cornflowers like the one I am wearing now. While there is no cost to members of Parliament the motor neurone disease community, including Mr Phil Brady, requests that members help to increase awareness of the disease within their electorates and within this place.

*Ask the
Experts
Monday 17
August 2009
West Ryde.*

*See page 2 for
more
information.*

Family Support Team

It's been a busy few months with a number of events and programs being held. This includes our Day of Hope and Remembrance, Care for Carers workshop and an information evening for people recently diagnosed with MND. It has been really good to be able to meet many of you at these events and we look forward to seeing you at others.

I guess my thoughts often turn to our regional members who are not able to attend our events in Sydney. We continue to look at ways that we can address this. Our regional advisors visit the regions and have been to the Central West, New England, Illawarra areas and to the mid north and far north coast of New South Wales over the last few months. Hopefully this has helped people put a face to the name of their regional advisor.

We have recently received good news, in the form of one-off funding from the Department of Ageing, Disability and Home Care, that will allow us to conduct some education programs in regional areas. Over the next 18 months we will be using these funds to provide outreach education to several of our regional areas.

The first regional educational event has already been planned for Ballina in July. It is a two-day program for carers (see p. 2 of this edition of *Forum*). Other regional events are at the planning stages and, depending on the program, will include days for people with MND and for their carers.

The aims of our education programs are to provide you with information that will assist you in living with MND and to provide you with knowledge about what supports and services are available, and how to access them. We will keep you informed about our future plans and are happy to hear from you about any suggestions.

Another major event is the 5th National MND Conference for health and community care professionals, being held in Sydney on 23 June. We are planning for an attendance of about 200 and so far the response has been very positive. The MND NSW Centre at Gladesville will be closed on Tuesday 23 June 2009 so that all staff can attend this important event.

Gina Svolos
Manager, Family Support

MND
Information Evening for those newly diagnosed. Tuesday 11 August at 6.30pm. Contact our Info Line on 1800 777 175 to RSVP.

Equipment

Loan and new equipment

Over the past three months there have been 274 loans of equipment to 105 members of MND NSW, free-of-charge. Equipment purchased includes five electric beds, three powered hoists with slings and specialised computer access and communication devices at a cost of \$35 800.

List of equipment in the MND NSW Equipment Loan Pool

A general list of equipment items in the MND Equipment Loan Pool is available upon request. This list does not provide details about currently available equipment as that can change very quickly. Items are loaned on a priority of need basis after you have been assessed and the item has been requested by a health professional.

Purchasing your own equipment

Sometimes specialised equipment is not available for loan through MND NSW or other equipment services and you may need to purchase an item yourself.

Before you make any decisions about this, we recommend that you first contact an allied health professional for the correct prescription of equipment needed. Allied health professionals include the occupational therapist, speech pathologist and physiotherapist. They are there to assist you and do not receive bonuses for recommending a specific piece of equipment. If you do not know how to contact an allied health professional, your MND NSW regional advisor can help you get in touch with one.

Once you are sure about the specific brand and item of equipment you need, remember to contact at least two equipment retailers before making a decision on your purchase. The Independent Living Centre of NSW (ILC NSW) is a great starting point for you to find retailers of specific medical equipment. ILC NSW does not sell equipment or accept commissions on the sale of equipment.

They are there to provide you with information about equipment and assistance with locating equipment retailers. They have an online product database and trained staff to assist with queries. Their extensive demonstration showroom is at 1 Fennel Street, Parramatta. You can make enquiries by email, fax, phone or face-to-face. To contact ILC NSW ph. 1300 885 886, email help@ilcnsw.asn.au or visit www.ilcnsw.asn.au. You can also speak with the MND NSW Info Line on 1800 777 175 if you have any equipment concerns.

Maree Hibbert
Equipment Services Coordinator

Carer Payment and Carer Allowance



The Federal budget had some good news for people on Disability Support Pensions and Carers Payment with an increase in rates. It was also announced that a \$600 supplement will be paid to people on Carer Payment and Carer Allowance. This supplement will be provided every year.

You may not know that carers may be entitled to assistance from Centrelink. Carers Payment is an income support payment for people who are unable to support themselves while caring for someone with a disability. The Carers Allowance is a supplementary payment for carers who provide daily care and attention for adults with a disability. This allowance is not income and assets tested and it is tax free. Contact Centrelink ph. 13 27 17 or see www.centrelink.gov.au.

Holidays and swap accommodation for people who use wheelchairs



Wheelies.net.au provides a free community service for people who use wheelchairs and who find it difficult to have holidays because of cost or lack of suitable accommodation. The website enables them to meet, talk and swap houses which they will know are suitable for their holidays. Australia-wide information. For more information see www.wheelies.net.au. Other online directories of accessible accommodation include: www.accessfinder.com.au, www.ideas.org.au/travel and www.australiaforall.com.au/.

For Sale

2001 Chrysler Grand Voyager RG auto, wheelchair accessible Freedom Van in exc. cond. 44,000 kms. Rego July 2009, parking sensors, window tint, A/C. Caringbah. \$41 500 ono. Contact Katie ph. 9531 2103, 0402 246 180 katielendrum@bigpond.com

Care for Carers

The Care for Carers workshop held over four consecutive Tuesdays in May was attended by 18 people who are caring for someone with MND. We had talks from health professionals on a range of topics and each day those who attended left with lots of new and helpful information.

The greatest value of the workshop is that it provides the opportunity for participants to meet with other people in similar situations, share experiences and have some time out. We are planning to run the workshop early next year, so if you might be interested in attending, let your regional advisor know.



Now what? Understanding grief



Palliative Care Australia's new booklet, Understanding Grief, briefly explores grief and has some ideas for how you can help yourself or others who have experienced loss. Available for free download at www.palliativecare.org.au or contact Palliative Care Australia ph. 1800 660055.

Better support for carers - report released

The Federal Parliamentary inquiry into better support for carers has released a report with 50 recommendations structured around six key themes. These are:

- o lack of recognition of the role and contribution of carers
- o difficulties in accessing information on the supports and services available, and a lack of assistance to develop the skills needed in their role
- o financial stresses
- o dissatisfaction with community care systems, particularly related to complexity, level of unmet need, cost, inflexibility and quality
- o lack of choice in relation to participation in the workforce or education due to service shortages and inflexible workplace practices
- o the physical, emotional and social impacts of caring.

A significant number of recommendations aim for greater recognition of the contribution of carers and to alleviate some of their financial and emotional stresses. Of note are proposals to develop national carer recognition legislation and a national carer strategy. For more information see www.aph.gov.au/house/committee/fchycarers/index.htm

Information Evening

We had 25 people attend our information evening in May. This meeting provides the opportunity for those recently diagnosed with MND, together with their family and friends, to find out more about MND and meet others in similar situations. The next information evening will be held on Tuesday 11 August at 6.30pm. Please contact our Info Line on 1800 777 175 if you would like more information or would like to register your interest in attending.

(left) Kevin and Marcia Bond with Maureen McGowan and (right) Margaret and George Lee at Care for Carers during May



If you don't have internet access and would like more information about items mentioned in Forum, ask your regional advisor.

Mailbag

Dear Editor,
On 17 March, as a special event, the Western Sydney support group met together for an outing on the Penrith riverboat. I decided to take our four children out of school for the morning to spend some quality time with their father Andrew who was diagnosed with motor neurone disease in November 2007. While on the boat we gazed at the sparkling water as jet skiers came up close and around the boat. You couldn't help but relax while watching the passing bushland and bird life. It was a memorable outing during which we had the added bonus of being surrounded by understanding and supportive people.

Then, when asked what Andrew would like to do on Easter Sunday to our surprise he wanted to go to the Sydney Royal Easter Show. How would I manage to pull this off I thought? With a quick phone call to the Show I reserved a scooter and nominated our daughter Jasmine aged 13 to be the driver. With a wide brim hat, sunglasses and an old fashioned lemonade to sip, Andrew was set. Andrew, Jasmine, Joel 7 yrs, Chloe 6 yrs, Olivia 4 yrs and I managed to stay nine hours and saw almost everything. It was a great day.

Our advice is don't worry what people will think, yes they do look, but mostly in amazement at seeing us all out having a great time.

Kath

Mount Riverview



Andrew with Joel and Chloe at the Easter Show

From Mummy, through Nicole

In memory of Sandra Cleary who died from MND in 2009. By Nicole, Sandra's daughter.

Don't look at me and see a loss
But remember me for who I was
Always there to have a laugh
Smiling, talking and going fast
Cause see in the end I was not me
I was trapped with MND
It was my body that kept me tied
It kept me trapped inside
But you see now I'm free
My body is not a part of me
I can fly and I can soar
Above the clouds and to you all
So happy times is what I want
Because I am not lost
I am free, my soul's escaped
And I am in a better place

Dear Editor,
I wrote the poem (below) after spending a day with Mum, not long after the realisation that she would never be able to speak again. I tried to find the positive in it, and acknowledge that there was so much that could be said with no words at all. It certainly doesn't negate the sadness, and the absolute torment that Mum - and everyone living with this same illness - must feel on a daily basis, but it gives me some comfort. Maybe it will help someone else too.

The unspoken

Through the words we cannot speak
In the silence you will hear
Perfection in the moments between
The unspoken

Like a melody played softly
On life's wildly spinning turntable
Defying eloquence and lilt
It's the unspoken

In the window of the soul
Eyes flicker like a silent film
We become audience to the miracle
Of the unspoken

Fear, frustration, love, truth
Are whispering in my ear
Yet not a word is heard
It's all unspoken

What you can and cannot say
Means little because I know
My heart and yours collide
At the unspoken

We laugh, we cry, we plead, we accept
And through it all I hear the sound
Of three words echoing, resounding
In the unspoken

Still so much there is to say
Yet in truth, it's all been said
Just one look and I am so grateful
For the unspoken...

Nicole Papisidero

29 December, 2008

FlexiRest

Just a reminder that funding is available for carers to have respite from their caring role. We mention this in every newsletter as we are really keen to encourage carers to use it to have a short break such as visiting relatives, going fishing, a dinner out with family, a massage, facial or perhaps a short holiday either with the person you care for or on your own.

This funding has been provided by the NSW Department of Ageing, Disability and Home Care and is a wonderful opportunity to have some time out. Talk to your regional advisor about FlexiRest.

You can write to the Editor, Forum, MND NSW, Locked Bag 5005, Gladesville NSW 1675 or email info@mndnsw.asn.au.

Support Groups

Northern Beaches

Our informal bi-monthly meeting continues to flourish and benefit from your continued membership and contribution, and we send an open invitation out to people in the area living with MND who have not yet come along.

At our last meeting, Trish Reynolds, Clinical Nurse Co-ordinator, Royal North Shore Hospital, was our guest speaker. Trish spoke about the importance of respiratory support and the benefits of bi-level ventilation for people with motor neurone disease.

We meet at the Palliative Care Cottage at Mona Vale Hospital and our next meeting is on 13 July, with guest speaker Irene Rulli, a dietician from the Northern Beaches. Hoping to see you there.

Jo Fowler

Regional Advisor

Central West

The Orange group, held bi-monthly at the Orange Ex-service's Club, is a warm and welcoming environment for everyone who has any association with motor neurone disease. We often have local health professionals in attendance and it is a great opportunity to get to know them, and the services that they offer, in a casual environment. The group is a great place to share ideas, emotions and concerns that surround each individual's MND journey. Our next meeting is on 11 August.

Jenny Judd

Regional Advisor

ACT/Southern NSW

At our meeting on 23 February it was lovely to see some new faces. We also welcomed Mary Brooks, a social worker who does some work at Claire Holland House and she led a discussion about 'looking after ourselves'. Mary highlighted the importance of taking the time to do things that we find enjoyable and we talked about how hard it can be to ask for and/or accept help. Members also talked about the supports and services they were accessing and how difficult it can be to understand and access health and community care services.

While I was away during April, the meeting was led by Anne Hogden, Speech Pathologist, ACT Health, Aged Care and Rehabilitation Team and Bronwen Binnington, Occupational Therapist, Palliative Care Services, Claire Holland House. Thank you Anne and Bronwen for stepping in. Our group will continue to meet every second month for the rest of the year and our next meeting will be on 29 June. If you are interested in attending please contact me for more details.

Iva Plessnitzer

Regional Advisor

Gladesville

Lorel Adams from University of NSW and Carolyn Cecere from the Anzac Research Institute were our guests for the April meeting. Lorel spoke about the DNA data bank donor program and some of the research that is being done at UNSW. Carolyn gave us an outline of the genetic research being done at the Institute with families that have the familial form of MND. Some of the group were happy to give a blood sample and a couple of hairs from their head to add to the DNA bank.

This was our biggest meeting so far with about twenty attending. All were very interested in the presentations on the latest research and enjoyed an opportunity to meet and get to know each other, strengthening their support networks. Support groups are a great place to meet and exchange information with others in an informal and friendly setting over a cuppa.

Our next meeting is on 5 August. In addition to welcoming members from the local area, the Gladesville group also welcomes those from other areas who would like to drop in. Contact me if you would like more details.

Caroline Gleig

Regional Advisor

Western Sydney

We had a lovely morning together during March, relaxing and chatting over a cuppa and scones while paddling the Nepean River on the Nepean Belle Paddlewheeler.

Thank you to proprietors for their special attention on the day and also to Interleasing, vehicle fleet and novated specialists, who sponsored the event.

Our next meeting is on 28 July and you are most welcome to attend.

Jenny Judd

Regional Advisor



On the Nepean Belle with Merv and Doreen Hibbert, above, and Margaret Lane (R) with daughter Alisha Limbrick (L) and Marty Terpstra, below.



MND Support Group meeting dates are listed on the MND NSW website at www.mndnsw.asn.au

My Story

by Denise Druitt

Book Review

Denise and her husband Gordon farmed rice for 40 years in Coleambally before retiring to Griffith in 2005. In the earlier parts of this autobiography we almost become part of the family as we get to know Denise, her family and friends. In March 2008, the Druitt's lives are turned upside-down with Denise's diagnosis with motor neurone disease. Having already come to know Denise and Gordon we travel with them through the ups and downs of this time, as they re-adjust their lives and together meet the many new challenges they face. In writing this book, Denise provides the reader with a personable story of her very full life. *My Story* is \$50, with net proceeds donated to MND NSW. To order your copy contact nicole@denisedruitt.com.au.



Penny Waterson

Information Resources Coordinator

Do you have a new general practitioner or neurologist? Let your regional advisor know, so that we can update your member information.

Support Group Contacts

METROPOLITAN

Ph: MND NSW 1800 777 175

Gladesville

Caroline Gleig - carolineg@mndnsw.asn.au

Northern Beaches (Mona Vale) and Northern Sydney (Hornsby)

Jo Fowler - josephinef@mndnsw.asn.au

Western Sydney

Jenny Judd - jennyj@mndnsw.asn.au

REGIONAL AND RURAL

ACT and Southern NSW

Iva Plessnitzer Ph. 6286 9900
ivap@mndnsw.asn.au

Broken Hill

Jamie Mitchell Ph. 08 8088 7123 (bh)
or 08 8088 1333 (ah)

Central Coast

Audree Dash Ph. 4384 2907
Sheila Holmes Ph. 4392 5513

Central West

Jenny Judd Ph. 1800 777 175
jennyj@mndnsw.asn.au

Illawarra

Robyn Petersen Ph. 1800 777 175
robypn@mndnsw.asn.au

Newcastle and Hunter

Noelle Smith or Eileen O'Loughlen Ph. 4921 4157
noelles@mndnsw.asn.au
eileeno@mndnsw.asn.au

Northern Rivers

MND NSW Ph: 1800 777 175

Family Support Calendar

30 to 31 July

Link and Learn Program Ballina

Two-day workshop for carers of people with MND at the Ballina Beach Resort, Ballina in Northern NSW.

19 and 26 October

Learn Now Live Well Gladesville

A two-day education and support workshop for people living with MND, their family and friends.

September (dates to be advised)

Learn Now Live Well Program Newcastle

A two-day education and support workshop for people living with MND, their family and friends.

11 August

Information Evening Gladesville

For people newly diagnosed with MND, their families and carers. MND NSW Centre Gladesville.

17 August

Ask the Experts West Ryde

An information day for people with MND, carers and friends.

For more information contact MND NSW Info Line 1800 777 175

If you would like assistance with travel to attend family support sessions or would like us to organise an MND information session in your region, please speak to your regional advisor.

Dates for the Diary

| | |
|-------------------|--|
| 26 May to 6 July | <p>Camino de Santiago de Compostella <i>Four MND Supporters will be participating in this famous pilgrim's walk. They will be walking 790 kms from the Spanish border – St Jean de Port – to the burial site of St James the Apostle at Santiago de Compostella. Contact Judith Witherdin to sponsor these intrepid walkers</i> judywitherdinglass@hotmail.com</p> |
| 21 June | <p>MND Global Day-Walk To D'Feet MND <i>Inaugural Canberra Walk beside Lake Burley-Griffin. Why not walk yourself or sponsor a walker to help raise funds. For further information contact Kym Neilsen ph. 8877 0999 or</i> kymn@mndnsw.asn.au or visit www.mndnsw.asn.au</p> |
| 4 August to 3 Oct | <p>A Drive for A Cure in memory of Norman George Jones <i>61 days34 Cities.....16000 Kilometres... 1 Goal: Drive around Australia in 8 weeks promoting awareness and raising monies to help find a cure. The drive will incorporate all major capital cities and various regional stops. For more information see</i> www.driveforcure.com.au</p> |
| 8 - 21 August | <p>Kokoda Challenge for MND <i>If you would like to find out more contact Kym at MND NSW on 8877 0912 or</i> kymn@mndnsw.asn.au or World Expeditions www.worldexpeditions.com.au</p> |
| 22 Nov | <p>Raising Hell on the Mountain Top for MND <i>Penny Leemhuis from Ballarat, Victoria, will be walking with close friends and personal trainers to the summit of Mount Kosciusko located at Thredbo. All monies raised will be donated to MND NSW in memory of David Tatnell. To sponsor a participant or create your own supporter's page visit</i> www.everydayhero.com.au/event/raisinghell</p> |

CITY SURF 9 August 2009

Are you planning to run for MND?

We can provide you with a special T-shirt and you can ensure your sponsors are able to support you easily through Everyday Hero. Contact Kym at MND NSW for more information ph. 8877 0999 or email kymn@mndnsw.asn.au

Wrapping up....

...MND Week 2009

Many wonderful volunteers gave up their time to sit or stand in shopping centres, railways stations, or out on the streets in towns all over NSW, selling MND merchandise and raising awareness about MND. It was a fantastic effort by everyone involved and we are extremely grateful for your support. Some new merchandise and a lot of determination by our great volunteers ensured that this years MND Week merchandise sales were a great achievement in such difficult times. Merchandise stalls raise not just much needed funds, but also community awareness about motor neurone disease.

Kym Neilsen and Ayse Dalkic
 MND NSW

'Homeleigh', Pymble
Open Garden Scheme 2-3 May
 by **Suzanne and Robert Ballinger**

We usually open our garden 'Homeleigh' to the public under the Open Garden Scheme in spring, but this year chose early May to coincide with the start of MND Week. There were a few anxious weeks beforehand when we wondered if it would all come together and we would have sufficient blooms to maintain people's interest.

Closer to the day, the weather became a concern as the weekend forecast was for showers which fortunately stayed on the coast. We did hear that some people did not come as they thought it would be raining in Pymble, however, except for the occasional clouds, the weather was very pleasant. Suzanne was very nervous about the radio interview on ABC 702 with Angela Catterns on the Saturday morning, but it went well and many visitors said when they had heard it they were inspired to come.

We need not have worried about the flowers as many were out and the leaves of those plants not in bloom also made attractive viewing. Our planting philosophy of trying to always have something in bloom somewhere, paid off. One disappointment was the eight metre tall tree dahlia which was in bud but still a feature, supported as it was by a triangle of thick bamboo poles. Three days later it is a mass of flowers!

We would like to thank Helena Karnolz for displaying and demonstrating her botanical art which added to the interest of the day.

The stalls in the driveway did brisk business selling plants, jewellery and MND merchandise and we thank all contributors and our neighbour's children who thoroughly enjoyed their success at selling raffle tickets.

Almost three hundred visitors sauntered across the lawns and along the meandering pathways. Many sat on the balcony or on the several seats scattered

cont'd next page

Global Day
WALK to d'Feet MND
Sunday 21 June
Lake Burley-Griffin, ACT.
See page 9 for more information.

MND Week 2009 (contd')

throughout the garden while partaking refreshments of soup, sandwiches, cake and tea or coffee. Afterwards, we commented that visitors seemed to linger longer than in previous years.

We wish to express a very big thank you to the many volunteers who manned refreshments, stalls and the gate and appeared to enjoy the atmosphere as well as the garden itself. The day could not have been the success that it was without their willing help and cheerful smiles. In addition, we sincerely appreciate the assistance received from MND staff.

Despite the effort and worry in the lead up, we get great pleasure from opening our garden which could be considered like a work of art that is of little value except when hung on a wall, shared and appreciated with others. But will we open again? In previous years we have said 'no', but who knows?



'Homeleigh'

Circular Quay

by Michael Fernandez

With buckets shaking, coins rattling and voices yelling we had some fun selling the merchandise and accepting donations. The encouraging part of the day was that a lot of people wanted to know about MND.

We had different characters volunteering and the Ranger responsible for wharf/foreshore area kept a watchful eye on us as we tried to collect as much money as possible. Everyone played an important role creating awareness of MND. Always in the back of our minds were our personal reasons for being there. We were thinking of loved ones lost and people who really need support and assistance.

We left Circular Quay Station happy and with smiles on our faces, feeling that we had contributed in a small way to get the word out about MND. Thanks to Sinead Brady, Greg Corr, Ian Zammit, Michele Zammit, Clive Hadfield and Therese Fernandez. If you are able to help out in the future, I recommend you doing so.

Qantas Terminal *by Megan Paton*

We had another successful year at Qantas' Domestic Terminal. We matched last year's sales even though there were fewer travellers than in previous years. We again were fortunate to have very generous friends and family who donated their time to both sell merchandise and talk to the public about MND; raising awareness of a disease that has impacted our lives, following my partner Scott's diagnosis with MND in 2001 and his death three years later.

As in previous years, the kids were the most victorious. Bridie and Phoebe Croxford were by far the most successful merchandise sellers, Bridie proudly declared to a number of people that she was only seven years old and that she had been doing Cornflower Blue Day for seven years (there were few who could resist her enthusiasm).

A special thank you to Suzie Overs who decided there was no other way to spend her 50th birthday but in blue. I've often heard it said that when times are tough people are more likely to give and I would definitely say I believe that to be true of this year. We also found that there appeared to be an increase in the awareness of MND – unfortunately it was often due to people having had friends and loved ones affected. At the end of the day we had a cold chardy toasting the day when there will no longer be a need for Cornflower Blue Day. Until then Bridie (like her cousins before her) will be able to boast a perfect attendance record I'm sure.

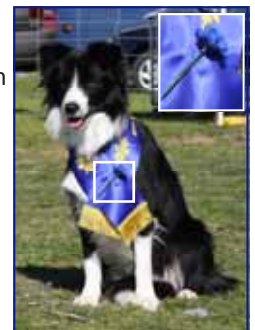
Dragonsmir Velvet Rose *by Edwina Bevk*

This photo is of my 9 month old Border Collie Velvet, Dragonsmir Velvet Rose, posing with her sash after winning 1st Place in 6-12months Sweepstakes at the Cootamundra All Breed Kennel Club last Saturday.

The prefix Dragonsmir is derived from my late husband's 'Slovenian' first name, Dragomir. We lost my husband, who was better known as Charlie, to MND seven years ago. As you can see the sash is fixed with a MND cornflower pin that we wear in support of MND at shows during MND week each year.



Yvonne Kenyon, Phoebe Croxford, Cooper Kenyon, Suzie Overs and Bridie Croxford.



Thank you to the volunteers who created a presence for MND at city and suburban locations during MND Week.

A very big thank you to everyone who has so generously given of their time to organise an event or help out at a merchandise stall during the past few months.

Danny Bergan Memorial Golf Day

The 2nd Danny Bergan Memorial Golf Day was held in hot conditions in late January at the lovely Carnarvon Golf Club, Lidcombe. This year's event saw 104 starters head out for a great day of golf. Over lunch Graham Opie, CEO MND NSW, was presented with a cheque. The day was an overwhelming success and the organisers would like to thank their major sponsors: Lion Nathan-Tooheys, Schweppes, St George Bank, Club Rivers and Stykris.

St Valentines Day Ball

A lovely evening was had by all who attended the annual St Valentines Day Ball in Dapto organised by the Illawarra Combined Seniors dance group. Over 120 people danced the night away with great music while enjoying the wonderful food and the company of their friends.

Friends of Geoff Hogg

Friends of Geoff Hogg held a two-day memorial bike ride in early March through the lovely Port Macquarie area. The motorcycle riders made many stops along the way collecting funds for MND NSW. Congratulations on a great ride.

Third MonStar Cup



The third MonStar Cup was held in late March at the picturesque Pennant Hills Golf Club. Once again the sun shone on MonStar and

we had a perfect day. About 150 golfers set out to enjoy an afternoon round of golf for all the right reasons.

This year, the Fiona Pearce Memorial MonStar Cup was cleaned up by the team from Steve Watt Constructions. In the evening the golfers relaxed and enjoyed great food, live entertainment and continued to show their support during the MonStar Auction.

Although the current economic climate added to the challenge of securing sponsors for the event, the organisers were very pleased with the results. Thank you to the major sponsors of this event: Bing Lee, Coca Cola Amatil/Blue Tongue Brewery, Enersys and GoldKey Financial; and also to the other companies and individuals who supported this event.

ACKNOWLEDGEMENT

We wish to thank Snap Printing, North Ryde for their generous support.

DISCLAIMER All care has been taken in the preparation of this newsletter. The MND Association of New South Wales disclaims any liability for its content. The information contained within is of a general nature. For medical advice, consult your doctor.

Food Services Industry Golf Day

The annual Food Services Industry Golf Day, in memory of Rodney Fay, was held in March at Carnarvon Golf Club, Lidcombe. A glorious day greeted the golfers with around 60 golfers teeing off. Wonderful support for this event was received from many companies within the industry and a presentation luncheon was held at the conclusion of the event. Thank you to everyone involved in organising such a great day.

Berry Quilters

The Quilters Club of Berry raffled a beautiful quilt in memory of their friend and member, Jennifer Johnstone. The quilt was on exhibition at Berry Pharmacy and tickets were sold over several weeks at the Berry craft markets. Jennifer's husband, Brian, has donated a further three quilts to be used for future raffles.



The beautiful quilt, made by Jennifer's friend, Shirley Blenkinsopp, was won by K Rees.

Speaking out about MND

Congratulations to Belinda Leabeater aged 12 years, finalist in the OzSpeak competition run by Baulkham Hills Council, who chose MND as the topic for her speech. In April 2007, George Lee, beloved Poppy of Belinda, died from MND. Belinda's grandmother, Patricia, told us, "we were so proud of her, in her school uniform with the blue cornflower pinned to her lapel". Thank you Belinda.



Belinda proudly wearing her cornflower pin.

Creatively using textiles

For her HSC major textiles project Ashleigh Worldon, created a costume inspired by her family's experience with motor neurone disease.

Ashleigh said she felt like her mum was with her helping her as she worked on the project because, "she was a really experienced sewer and taught me everything I know today... I miss her everyday and I really want to celebrate her life. The photos you see on the outfit are of my mum". Well done Ashleigh.



Ashleigh's costume was inspired by her mum.

Have you thought of becoming a MND NSW volunteer? For more information contact Ayse Dalkic ph. 8877 0999 or aysed@mndnsw.asn.au.

Editor: Penny Waterson