

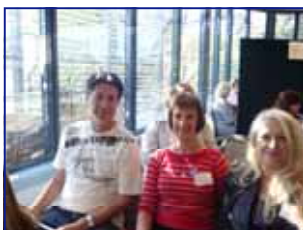


FORUM

Ask the Experts 2009



*MND NSW
Regional
Advisor,
Caroline Gleig
with Paul and
Sandra Tosolini
(left)*



*Michael Watkins, Sue
O'Reilly and Zora
Razmilic-Fisher (left)
and Teresa Lawton,
Gary Lawton and
Helen McKee-Wright
(right)*



*John Schuback, Roger
Pamphlett and Steve Vucic*

The annual MND NSW 'Ask the Experts' Forum for members, their family and carers was held during August at the Ryde-Eastwood Leagues Club. Over 60 people attended the information sessions throughout the day asking many questions around the focus topics of motor neurone disease research, superannuation and percutaneous endoscopic gastrostomy (PEG).

Dr Steve Vucic, of the Multidisciplinary MND Clinic St Joseph's Hospital and Department of Neurology Westmead Hospital, Western Clinical School, University of Sydney, started the day with an overview of motor neurone disease, including video footage of diagnostic testing and information about research in which he is currently involved. Associate Professor Roger Pamphlett, of the Faculty of Medicine, University of Sydney, continued the morning session with more specific information on Australian and overseas research into familial and sporadic MND. Australian researchers in MND are well represented in the international research community.

Over lunch those present were able to chat with MND NSW staff, the speakers and other members and families.

Josh Mennen, of Maurice Blackburn Lawyers, opened the afternoon session with an outline of superannuation and insurance issues for people who have life-limiting conditions. He explained that for some people, compulsory superannuation schemes may also include insurance cover by default, and that it could be very worthwhile to review the annual member statement issued to you by your superannuation scheme.

Margie Zoing, MND clinic nurse at Calvary and Prince of Wales Hospitals, explored issues people might need to think about when considering PEG. She also explained how the feeding tube is placed through a small incision near the navel, how the liquid feeds are provided and about the day-to-day care of the tube and abdominal skin. Those present were very interested to see and touch the different types of tubes that Margie brought along with her on the day. Our final expert for the day was Professor John Hodges, of Prince of Wales Medical Research Institute, who discussed the spectrum of cognitive and behavioural changes in MND, including preliminary findings from his recent study into frontal-temporal dementia and MND, that had involved many MND NSW members and carers.

Throughout the day the sometimes confronting information provided by our experts was very well received by the audience and was offset by the relaxed atmosphere during the sessions and breaks. There were many questions from participants to the experts during the allocated question times and most of the speakers were also able to stay during the breaks to answer individual concerns.

Also on the day, close to half of those present donated blood and hair samples to the MND DNA Bank Donor Drive. If you were unable to attend Ask the Experts and would like to donate your blood to the Bank please contact Lorel Adams, MND DNA Bank ph. 9036 5456 or email ladams@med.usyd.edu.au.



*Daniela Baretto of the
MND DNA Bank with Greg
Thomas*



*Jane Cabique with parents
Carol and Peter Rofey*



*Judith Chidgey, Ian Palmer
and Aimee Palmer*



**WALK to d'Feet MND
Sydney Olympic Park
Sunday 8 November 2009**

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.

A Message from the CEO

The 5th National MND Conference, hosted by MND NSW in June, was an outstanding success. Over 240 health and community professionals from Australia and New Zealand attended and in this edition of *Forum* we feature several articles from the proceedings.

The Conference is held during the week following MND Global Day, the winter solstice, each year. To coincide with Global Day 2009, a motor neurone disease community service announcement (CSA) was run on all major television stations across Australia. The CSA featured Stephen Hawking and was produced by ALS Israel. It was adapted by MND Australia for Australian television.

Robert Attwood, a member of MND NSW, wrote to us about his reaction to the advertisement:

I'm sure the MND television advert project involved many, many people, to whom I wish to send my sincere congratulations... When I first saw the advert screen, I experienced a mixed bag of emotions, initially fear around my own life span of one to five years, now I've lived with motor neurone disease for four and a half years.

However, this fear soon turned to immense joy as I witnessed a great awareness raising campaign, for motor neurone disease, on the television. On the television!

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

You can join us in Sydney for the Walk to d'Feet MND on Sunday 8 November. Authorities at Sydney Olympic Park have allowed us to increase numbers to 500 participants, so register early to ensure your place. See page 12 of this edition of *Forum* for more information.

Why not organise a local Walk to d'Feet in your local area? It is a great way to bring a community together and raise funds and awareness for motor neurone disease. For a complete 'how to' kit contact MND NSW ph. 8877 0999.

A group of intrepid individuals have taken Walk to d'Feet to a whole new level by walking the Kokoda Track to raise funds for MND. A full report of their walk will appear in the next edition of *Forum*.

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



On Sunday 21 June a hardy crowd of over 100 people braved a cold and wet morning in Canberra to Walk to d'Feet MND. The walk was a joint endeavour of MND Australia and MND NSW, and a resounding (and drought-breaking) success.



See back page
for more
information

MND NSW

Building 4 Old Gladesville Hospital
Gladesville NSW 2111
(Locked Bag 5005
Gladesville NSW 1675)

Phone: 02 8877 0999

or 1800 777 175

Fax: 02 9816 2077

Email: admin@mndnsw.asn.au

www.mndnsw.asn.au

ABN 12 387 503 221

PATRON

*Her Excellency Professor Marie Bashir AC
Governor of New South Wales*

VICE PATRONS

Paul Brock AM

Melinda Gainsford Taylor

Kevin Langdon OAM

The Hon. Mr. Justice Peter W. Young

Auditor

C.M.Pitt & Co.

Solicitors

Mallesons Stephen Jaques

MND NSW BOARD

President

Phil Bower

Vice Presidents

Roger Henshaw and Janice Scheinecker

Secretary

Bob Howe

Treasurer

Robert Templeman

Board Members

Alex Green, Gary Jacobson, Nick

McLoughlin, Ralph Warren

Chief Executive Officer

Graham Opie

Office Coordinator

Petra Sammut

Administrative Assistant

Anne Jones

Accountant

David Radford

Fundraising Manager

Kym Nielsen

Fundraising Assistant

Ayse Dalkic

Family Support Manager

Gina Svolos

Family Support Coordinator

Jane Barrett

Regional Advisors

Jo Fowler, Caroline Gleig, Jenny Judd,

Eileen O'Loghlen, Robyn Petersen,

Iva Plessnitzer, Noelle Smith

Information Line Advisor

Suzanne Rymer

Equipment Service Coordinator

Maree Hibbert

Equipment Assistants

Matthew Fowler

Michael Walker

Information Resources Coordinator

Penny Waterson

Family Support Volunteer Program

Coordinator

Greg Colby

And..... many valued volunteers

Members'
Christmas Party
Saturday
21 November
3 to 5 pm
MND Centre
Gladesville.
To RSVP phone
1800 777 175.

Family Support Team

It has been a busy time for the Family Support Team over the last few months with several major events being held. In June, MND NSW hosted the 5th National MND Conference and in August we held our annual Ask the Experts Forum for people living with motor neurone disease.

The Conference theme was CARE - Care, Advocacy, Research and Excellence. The first presenter was Leonie Duroux, partner and carer of Marbuck Duroux who has lived with motor neurone disease since 2004. Leonie shared their experiences and her very heartfelt account set the scene for the conference. The audience really appreciated hearing directly from a carer, with comments such as '*Leonie was inspirational ...I commend her for her strength and courage to share such personal stories*'. Thank you Leonie for sharing this and making a difference to those who care for people with MND.

Professor Matthew Kiernan from the Multidisciplinary MND Clinic at Prince of Wales Hospital spoke about research developments in motor neurone disease.

Petrea King, of the Quest for Life Foundation, completed the first session with her talk, 'The Heart of Caring'. She encouraged health and community professionals to maintain their resilience in caring by looking after their own physical and emotional health.

The remainder of the day continued to be informative and the conference was evaluated highly by those who attended. We have reproduced Leonie's talk and a summary of Professor Kiernan's presentation on pages 4 to 6 of this edition of *Forum*. There is also more information from the conference on our website at www.mndnsw.asn.au.

The feedback from the members, families and carers who attended 'Ask the Experts' was very positive with comments such as, '*great speakers*' and '*...opportunity to ask questions raised some interesting points*'.

Other recent Family Support Service events include the Link and Learn Program for carers conducted in Ballina during July, and a Learn Now Live Well Program for members and carers, which was held during early September in Newcastle.

Several other events are scheduled including educational days in Port Macquarie, Orange and Gladesville, and our members' Christmas Party in November. Please see our Family Support Calendar for further details.

Gina Svolos
Manager, Family Support

Equipment

With the warmer weather just around the corner, planning for holidays often starts. If you are using a wheelchair it is important that, before you make a booking, you check the accommodation has features that make it accessible.

Are the external and internal doorways wide enough? The average width of a manual or powered wheelchair is 65-68cm.

Are there any steps into the accommodation? If there are, ask if there is a room without steps or some portable ramps on site to assist.

Is there enough room inside the room and the bathroom to easily manoeuvre the wheelchair? The area surrounding doorways needs to be wide enough and have enough room so that the wheelchair can turn. There also needs to be enough room inside the bathroom so that the door can be closed for privacy when in use.

Is there a hob around the shower or is the shower over the bath? Hobless showers are the most suitable.

Beach wheelchairs are available for hire from many local councils, however, phone ahead to reserve a chair to avoid disappointment. MND NSW has one beach wheelchair available for short-term holiday loan to members.

If you need large items of equipment such as electric medical beds, shower commodes and hoists, they are often available for hire from local equipment suppliers, who will also deliver and setup the equipment for you.

As you would for any holiday, plan ahead and check before you travel to avoid disappointment. A phone call or an email can save a lot of distress. Generally, staff can accommodate most requests if they are notified in advance. The Ideas website at www.ideas.org.au provides more information on accessible services.

Maree Hibbert
Equipment Services Coordinator

Vale

Dr Dawn Thew

*Founding President MND NSW
Founding Chairperson MND Research Institute of
Australia*

Dawn Thew died on Wednesday 2 September.

The MND community is indebted to Dawn for her contribution in helping to establish not only MND NSW, but also the MND Research Institute of Australia.

5th National MND Conference

At the 5th National MND Conference, the first presenter was Leonie Duroux, partner and carer of Marbuck Duroux who has lived with motor neurone disease since 2004. Leonie's words are reproduced in full here.

Leonie Duroux

Firstly, I wish to acknowledge the Eora people, the traditional owners of this land, the elders past and present, and thank you all for giving me the opportunity to share Marbuck's story.

My name is Leonie Duroux and I am a carer for my partner Marbuck who suffers from MND. We live in Macksville on the beautiful Mid North Coast of NSW. Marbuck is a 36 year old Kamilaroi Man who grew up in Tenterfield in northern NSW. We have two children, Little Marbuck aged 14 and Elijah aged 11 who both play very important roles in caring for their dad.

I would like to spend a few minutes to talk to you about Marbuck and his illness and the effects this has had on him and our family.

On 27th October 2004 (a day I will never forget), after having symptoms for about 16 months previous, Marbuck was diagnosed with Motor Neurone Disease. At the time I had some idea what MND was, but neither of us knew what effect it was going to have on our lives or what was going to be in store for us. The neurologist just 'wrote him off'. I still don't know whether that was because he was racist or just simply because he had no bedside manner. He sent us on our way in a very confused state and didn't provide us with any information about services available, counsellors or even a contact for the local MND society and of course we were in no frame of mind to know what to ask for. He told us there was medication but in his opinion, it was no better than a placebo and that Marbuck wasn't eligible to get it on the PBS anyway (it turned out he was). It is a testament to Marbuck's strength of character, his stubbornness (which sometimes drives me crazy) and the fact that he remains in his own home that he has defied the doctor's predictions. Although he no longer takes riluzole, I also believe that it has played a part in Marbuck still being with us today. Even though the good doctor predicted he would need a feeding tube and ventilator within 3 months and would be dead within 6 months, he didn't receive his first PEG tube until 14 months after diagnosis and has hardly needed breathing support. Needless to say we haven't seen a neurologist since, but receive wonderful support from our GP.

At first there was no information, but I started spending ages on the net gathering as much info as I could, so much so that my brain would go fuzzy. In the end I had to put it down and deal with the reality of what was happening here and now and

know that the information was there to go back to when I needed it. I do believe being informed is a good thing because it means being prepared. But preparing yourself one step at a time is a much better idea. Without being informed you live in ignorance and when you live in ignorance needs do not get met.

It was a massive learning curve for the family. The hardest thing I have ever had to do in my life and I am sure Marbuck would agree was to tell the family of Marbuck's prognosis. Some people would be aware that Marbuck's younger brother was murdered in 1991 in Bowraville ...the thought just kept running through my head ...my father-in-law and the family had already been through so much, how was I going to tell them they are going to lose yet another precious member of their family.

Marbuck's way of coping with constantly living with this life sentence has become to joke and laugh a lot. A lot of people cannot understand how someone like Marbuck would find anything to laugh about, but he laughs often and sometimes until he chokes (which never deters him). We made the decision when he was diagnosed to try and laugh

everyday. This doesn't always happen – we are a normal family. We still give each other the silent treatment, I am still a bitch and we still get frustrated with one another.

Anyone that knows Marbuck knows he is a mad Holden man, his favourite car is a HK Monaro, so his wheelchair is affectionately known as a Monaro and has a Monaro badge on the back. Before he got sick he always had his head under the bonnet of a car and always had two or three cars going at the same time (which used to drive me and the local mechanics up the wall) – so his way of coping was to make jokes along the lines of "there's something wrong with my motor" or "God got pissed off with me because I kept fixing everyone's cars, so he gave me a motor that nobody could fix".

Coping with these dramatic lifestyle changes requires heaps of communication. Marbuck has been very open and honest about the fact that MND is a death sentence. I can't imagine how much harder it would be if we didn't have that honesty between us or if one or both of us weren't facing reality. We have also tried always to be honest with the boys – we are both aware that the way we deal with this could make or break our children.

(Continued on page 5)

*The MND NSW
Annual
General
Meeting will
be held at 3pm
on Tuesday 27
October at the
MND NSW
Centre,
Gladesville.*

5th National MND Conference (cont'd)

(Continued from page 4)

Everyone here would know how living with MND dramatically changes your lifestyle. So many things that we as able-bodied people take for granted becomes a huge task. Scratching your nose or wiping your eye. Not being able to roll over in bed – not being able to just go out whenever you want. Making sure you are prepared and comfortable when travelling and that there is access wherever you go. When I get frustrated, I try to think about what it would be like not being able to do even the simple things and it snaps me out of my selfishness.

The kids miss out on so much. Kids of MND parents don't get to go out and do a lot of things that a lot of kids again just take for granted, and they are also in a position where they have to experience and do a lot of things that children should never really have to face. Our oldest son was fortunate enough this year to gain a scholarship so he is at boarding school. This was something we really thought about long and hard, but we also wanted to allow our son who has given up so much of his time for his father and more or less put his life on hold, to just be a kid and take advantage of this wonderful opportunity; as his father so eloquently put it, "you have to go and make me proud". Both kids are now experts in PEG feeding and Little Marbuck can utilise the hoist. Elijah can use the hoist, but his concentration span isn't very good, but having said that, he has taken on a lot of the responsibility as the man of the house since his brother has gone to boarding school and I can't even begin to say how proud I am of my two children.

I could give many, many examples and tell a lot of little stories, but my time is limited, but I would like to share a couple more. Just after Marbuck was first diagnosed our dog, Junior, had been missing for a couple of weeks and despite our best efforts to find him we were unable to. One day I was walking and happened to walk past a house and this young man had come to answer the door to somebody and a dog ran out. This young man called out to 'Jack' to come back and of course Jack didn't come (because as it turned out Jack was actually Junior our dog), so while the boys were at school I managed to retrieve Junior (legally) and take him back home. On the way home from school that day I said to the boys, "I have a really fantastic great surprise for you when you get home" and the boys said, "what is it?" and I said, "Oh it's really deadly, you'll love it" ...and there was this back and forth - you know how kids are, they tried to guess what it was and plead for me to tell them and I just kept saying, not telling ya....wait til

you get home and all of a sudden, Elijah who was 6 at the time looked up at me with this excited face and said, "Oh is Dad all fixed up?", and my heart fell down to my knees. Having Junior back was pretty cool, but really there is no comparison is there?

There is a general lack of understanding of MND and this is a challenge. For us and for Marbuck being an Aboriginal man, the old stereotypical racist attitude does sprout its head from time to time. When Marb's speech was starting to slur people would automatically make comments that would suggest "he's a blackfella", he's got to be off his face or drunk". One example of this was one day last year we were visiting Marbuck's father and we were getting Marbuck in the car ready to go. The police pulled up for some reason. As we drove away one young ignorant cop said, "Oh he looks like he's had a bit too much to drink". The officer was lucky that I didn't hear him and I'm glad I wasn't around to hear what my brother-in-law

and father-in-law said to him, but I think he got an education that day.

"...but they do not understand MND."

Sometimes the challenges we face are that people understand a stroke or heart attack or cancer, but they do not understand MND. They do not get that while Marbuck and others like him

cannot physically function, his mind remains unaffected and he still knows what he wants and is still able to make decisions in relation to his care and raising of our boys; he just can't articulate it. When I am on respite, the boys do not ask permission to do something of the homecare worker – they ask their dad and he can move them to their room with one look if they are misbehaving.

Each one of these providers serve a different but valuable purpose in our day to day lives. Without this help I would not be sane and Marb would not be able to maintain the little bit of independence that he has. Many people may be able to identify with this, but there seems to be a common view and this also goes back to the previous slide that people like Marbuck belong in a hospital. If I shoved him in a hospital he would be dead. Hospital is not a suitable place for him to be. There are days when Marbuck has many choking/vomiting/coughing attacks. In hospital he would not be able to alert anybody he needed assistance, it would be undignified and detrimental to his health and wellbeing, so this is why these service providers play such an important role in Marbuck's care.

I've touched on most of these things already. Marbuck needs to feel that his rights are being

(Continued on page 6)

MND

*Information
Evening for
those newly
diagnosed is
Tuesday 17
November at
6.30pm.
Contact our
Info Line on
1800 777 175
to RSVP.*

5th National MND Conference (cont'd)

(Continued from page 5)

respected. The support we gain from family and friends is invaluable no matter how insignificant it may seem to them. I have a friend in Coffs who lost her husband last year to MND. When I talk to her the weight of the world lifts off my shoulders because she knows exactly what I am going through. A big problem for people with the sorts of dilemmas that we face is that we do not know what services are available to us, who to turn to and how to access them. Being informed makes a huge difference, as does surrounding yourself with positive people so you get the emotional support you need. Being able to take respite breaks with a minimum of fuss also makes a massive difference. The slogan for the MND Association is 'Never Give Up' and I think Marbuck has taken that to heart. One night about 12 months ago when I was putting Marbuck to bed he said to me, "every night when I go to sleep I hope I don't wake up, but when I do I look at the kids and I'm glad, but I'm also sad because I have to do it all again". ...this is a fight and we feel like we are fighting a losing battle, but the help and support of people like our case workers, our support from the MND Association, our GP, our health workers, homecare workers, and our friends and family, all makes it that little bit easier for Marbuck and others like him to "do it all again". I thank you very much for your time today and allowing me to share with you something that is very close to my heart. Thank you.



Sail on
Sydney Harbour
with MND NSW
and
Sailors with
DisAbility

Sunday 18 October
11am to 2pm

Enjoy some time out on Sydney Harbour with the friendly volunteer sailors on this magnificent, wheelchair-friendly boat.

The MND NSW Sailors with DisAbility cruise has been popular in the past and numbers are limited to 12 people. There is no charge to attend.

Jo Fowler and Caroline Gleig, MND Regional Advisors, will be with you on the day. The cruise departs from, and returns to, Rushcutters Bay.

Contact MND NSW ph. 8877 0999 if you would like more details or to register your interest.

Professor Matthew Kiernan of the Multidisciplinary MND Clinical Service at Prince of Wales Hospital and the Prince of Wales Medical Research Institute, spoke at the Conference about research developments in motor neurone disease. This is a summary of his presentation.

Matthew Kiernan

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

Advances in our understanding of the glutamine neurotransmitter system and the discovery of causal genes linked to the development of familial motor neurone disease (MND) have re-ignited research interest. Problems related to clinical heterogeneity have been identified – not all MND is equal. It has become clear that survival in MND is determined by many factors, including the clinical presentation (phenotype), rate of disease progression, the early presence of respiratory failure and the patient's nutritional status. Further improvement in survival seems dependant on improving our understanding of the pathogenesis of MND, leading to the development of early and specific diagnostic methods and the discovery of therapies that not only slow the progression of the disease, but also address the secondary consequences of respiratory failure and malnutrition.

In terms of key needs to facilitate future clinical trials and thereby treatments, without a definite test to diagnose of MND, neurologists are hampered by continuing to rely solely on purely clinical criteria for diagnosis. While newer imaging techniques have shown promise in aiding diagnosis, the role of imaging at present remains primarily to exclude other conditions. The development of novel biomarkers to objectively assess disease progression will greatly refine treatment trials (and significantly reduce trial costs). In addition, the power of population registries such as the Australian Motor Neurone Disease Registry are being increasingly recognised. This local registry forms part of a growing worldwide trend to obtain epidemiological and natural history information for MND, and provides a hub for collaborative approaches. These collaborative endeavours will inevitably lead to a better understanding of MND, its progression in different patients, and to the development of guidelines for improved care of MND patients. As inevitably occurs with greater research focus, the potential for new therapies and approaches are being realised. In contrast to the previous century of limited progress in the field of motor neurone disease, these more recent developments offer realistic hope that new treatments will emerge.

We are currently auditing the books in our MND library. If you have any books on loan could you please return these as soon as possible.

Bob's story

Excerpt reprinted from The Lismore Northern Star

‘ Geoff Irwin and Bob Delaney were the silent players in Marist Brothers’ round 13 clash with Mullumbimby. In that July match, Brothers donned pink jerseys and auctioned them off to raise funds to help the former players suffering from motor neurone disease. To give an insight into the struggle faced by both men and their families, Delaney has written about his experiences. Delaney was diagnosed with MND in April 2005.



Bob Delaney tackling on the field

“I remember asking God, out loud while driving one day ‘Why me Big Fella? In 50 years I’ve had no sickness beyond a bad case of the flu ... the first time you give me a real challenge, you give me no out! Fair go. Give me something I can at least fight’.”

On the day of the diagnosis, I was by myself and I had a two-hour drive home. To describe that trip as bleak belies the nature of despair and the loneliness any ill person feels. No matter what one does, no matter how much compassion and sympathy one has, no one can share the way you feel. Strangely, I thought much of suicide, but not seriously of committing suicide. I remember literally saying to myself: “Well, if you’re going to top yourself, now would be the time”.

However, what you imagine life to be like with MND is far worse than the reality. You imagine life with a serious illness to be 100 per cent down and depressed. But most of the time things are routine, normal and happy.

Physically, MND presents challenges as you become less mobile and your muscles weaken. My initial weakness was in the throat so speech has become increasingly troublesome. Those who know me can understand me but call centres from India have some trouble.

I have a friend who is hard of hearing and with me being hard of speaking, it makes for interesting conversations. The things that are most frustrating are things like doing up buttons, getting up from really comfy, soft lounge chairs, playing guitar badly, unscrewing lids on bottles, buttering bread and trowelling on vegemite, even picking up the soap. However, if you like vegemite, you do learn to innovate.

I have also found my emotions are quite fragile and I find myself crying when people say nice things and show obvious concern and affection. But that’s okay. However, if I try to rouse on my daughter, I cannot keep a serious face and I tend to crack up laughing. What’s worse is she has worked this out and seems to be exploiting it!

Rarely, but every now and then, I have these, what I call ‘why me?’ moments. They are an indulgence which I do not wallow in and recognise for what they are: moments of self-pity. But they are human and I accept that too.

One event had a profound effect on me within a week of being diagnosed. There was a motor accident in Mullumbimby on Saturday night in which two 19 year old boys were killed. I recall thinking at the time that on Friday, these guys would have been having a great time, planning what to do with their lives. And now they were dead. On Friday I was in a black hole but now I was alive. What a waste it would have been if these boys had spent the previous week feeling sorry for themselves about anything. What a waste it was for me to be lamenting something I couldn’t change. So, for most of the time at least, the glass is half full, not half empty.

The most challenging aspect of living with MND is accepting the prognosis and at the same time, maintaining hope. They do seem to be mutually exclusive! I certainly get anxious and bluesy about my predicament, but my downs are no worse in degree than before diagnosis. And my good times are equally as good. Also, and most importantly, you are reminded of the real treasures we possess. That is family and friends. I don’t think I took my family and friends for granted previously, but I was reminded how important they are because without the support and affection shown I would have continued to feel dangerously alone. So the one thing I have to thank MND for is the wonderful and uplifting affirmation of affection I have received from so many people. And if you have a friend doing it very tough you can support them in many ways. You don’t have to visit that person necessarily, but a note or an email saying they are in your thoughts is most encouraging.

I remember at a party 20 years ago meeting a bloke and was about to ask “And what do you do?” I stopped myself, thinking it doesn’t really matter. As silly as I know it is, men tend to define themselves by what

they do – their careers but also in leisure. And probably the hardest thing to cope with is the idea that you can’t do things anymore. So, occasionally you have feelings of being useless and being a burden and, while I know they are stupid thoughts, you can’t help how you feel.

So, you have to think about what you can do, not what you can’t. Your glass is half full, not half empty. ‘‘



Bob and his family in 2004

If you have suggestions for books for our library please let us know. Contact Gina Svolos, Manager Family Support Services, ph. 1800 777 175.

Support Groups

Kingswood

The recent Kingswood meeting was very well attended as there had been considerable interest in our guest speaker, Kristina Dodds, from the Home Hospice Program. Kristina spoke about how having a mentor can help a person care for someone with motor neurone disease with increased skill, support and flexibility, in the home. A mentor from the program was also at the meeting and she spoke about the rewards for mentors and families, when they are linked by the program. There was a lively discussion and great sharing of ideas and thoughts on the Program and on care in the home. We also shared a lovely afternoon tea - as we usually do.

Our next meeting on 29 September will provide a great opportunity for you to chat with Graham Opie, MND NSW CEO, who will be attending.

Jenny Judd

Regional Advisor

Northern Sydney (Hornsby)

Our next meeting will be on 8 October and I look forward to seeing you there.

I am hoping that as many members as possible from our group will be able to attend the MND NSW Christmas Party on 21 November at Gladesville, because we will not be able to meet in December, as previously planned. This is because I have received some exciting news that a paper I have co-authored has been accepted for presentation at the International Symposium for ALS/MND and the Allied Professionals Forum in Berlin in early December.

The Christmas Party is always a great time for members to catch up with old friends and new, and to meet with staff and volunteers from the Association, so please mark the date in your diary.

Jo Fowler

Regional Advisor

Central Coast.

The Central Coast Support Group continues to meet bi-monthly on a Saturday afternoon at the Niagara Community Centre. The next meeting will be held on 17 October and the final meeting for the year is on 12 December. This group is for members, their families and their caregivers who live on the Central Coast. Several dedicated past carers and supporters of MND NSW also attend, supporting others at the meeting and, to the delight of those present, providing a delicious afternoon tea.

The group extends a very warm welcome to new members and their families - come along and learn more about living with motor neurone disease. For more details contact Audree Dash, Support Group Coordinator ph. 4384 2907 or Jo Fowler, MND NSW Regional Advisor for Northern Sydney and Central Coast area ph. 1800 777 175.

Jo Fowler

Regional Advisor

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 7093 (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

MND NSW ph. 1800 777 175

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

*Our new website
was launched in
July.*

*Visit
www.mndnsw.asn.au*

Do you live within travelling distance to Orange?

MND Information Day for Members and Families

Orange Ex-Services Club on 13 October 2009

Would you like to know more about motor neurone disease, MND NSW, accessing services, specialised equipment to assist people living with MND and managing breathing difficulties?

To RSVP or for more information contact
MND NSW ph. 1800 777 175.

There is no charge to attend.

Some assistance with travelling costs and overnight accommodation may be available to enable members from a broader geographic area to attend.

Noticeboard

Young Carer Study 2009



The Social Policy Research Centre (SPRC) at the University of New South Wales, is conducting a study about children and young people aged 12 to 25 years who are caring for a person with disability or chronic illness. The researchers are interested in finding out more about the lives of young carers and the people they care for.

Young carers (12-17yrs), young adult carers (18-25yrs) and people (aged 18 and above) receiving care who express interest will be invited to participate in an individual interview of about an hour's duration either face-to-face or by phone and asked to complete a short questionnaire. If you would like more information about this study contact Samia Michail ph. 9385 7800 or email s.michail@unsw.edu.au by 15 October 2009.

Your health website



The Australian Government Department of Health and Ageing has launched a new website for people to use to find out about health reforms and provide comment and feedback to the Government about their own health experiences and ideas. Visit www.yourhealth.gov.au.

Advanced care planning forums - Western Sydney

29 September, 10am-1pm, Bankstown
13 October, 10am-1pm, Campbelltown
Sydney South West Area Health Service is conducting two forums to provide information about substitute decision-making, powers of attorney, enduring guardianship and advance care directives. There is no charge to attend, but you must RSVP at least 5 days before the event. Contact Heather Byron ph. 4654 6306 or email heather.byron@sswahs.nsw.gov.au.

Learn Now Live Well

For people with motor neurone disease,
their family and friends

19 and 26 October 2009

10 am to 3 pm
Gladesville

Learn Now Live Well is a two-day educational program held over two weeks on consecutive Mondays. You will learn about living well with motor neurone disease and the services available for people living with MND.

Contact MND NSW ph. 1800 777 175 for further information and registration details.

There is no charge to attend.

Back to Basics - Handy Hints for Carers to Help Prevent Back Injuries



The book, 'Back to Basics', demonstrates a variety of ways to move the person you are caring for and explains how to minimise the risk of injury.

Veterans or those caring for veterans can obtain a free copy by phoning 133 254 (metropolitan) or 1800 555 254 (non-metropolitan).

Others can view or download free online at www.dva.gov.au/aboutDVA/publications/health/Pages/back%20to%20basics.aspx

Family Support Calendar

13 October	MND Information Day for Members and Families - Central West NSW <i>Orange</i>
14 October	MND Directions in Care for Health and Community Care Professionals - Central West NSW <i>Orange</i>
18 October	Sailing on Sydney Harbour with Sailors with DisAbility <i>Places limited - register your interest now.</i>
19 and 26 October	Learn Now Live Well Gladesville <i>A two-day education and support workshop for people living with MND, their family and friends..</i>
17 November	Information Evening Gladesville <i>For people newly diagnosed with MND, their families and carers. MND NSW Centre Gladesville.</i>
21 November	Members' Christmas Party Gladesville
December (date to be advised)	MND Information Day for Members and Families Port Macquarie

For more information contact
MND NSW Info Line ph. 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.

For more information about events on the Family Support Calendar contact the MND NSW Info Line ph. 1800 777 175.

Dates for the Diary

25 September	Legends of League Luncheon <i>Steelers Club Wollongong</i> Contact Peter Fitzgerald at pfitzgerald22@bigpond.net or ph. 0412 263733
17 October	MND Fundraising Dutch Auction and Dinner <i>Junction Inn Hotel, 2 William St, Raymond Terrace. Contact Kerrie Skeffington ph. 0407 681 832</i>
24 and 25 October	Ray McDougall and Margaret Burge Charity Weekend <i>Annual event held at South West Rocks. The weekend features a Saturday evening auction and a Sunday golf day, including a major raffle. Contact Bruce McDougall ph. 6566 5402 for more details.</i>
25 October	Lions Pride Car Show for MND <i>St Marys Rugby League Club Car Park, St Marys. Contact Mark Davies mvdavies@optusnet.com.au</i>
8 November	Walk to d'Feet MND <i>5km walk at same venue as last year's event, around the lovely Blaxland Riverside Park at Sydney Olympic Park. Visit www.mndnsw.asn.au for more information or contact Kym Nielsen ph. 8877 0999 or kymn@mndnsw.asn.au.</i>
14 November	MND Charity Golf Day <i>Cooma Golf Club. Contact Val Young ph. 6452 5027</i>
22 November	Raising Hell on the Mountain Top for MND <i>Fundraising walk from Thredbo Village to the top of Mt Kosciusko. Contact Penny Leemhuis ph. 03 5338 7156. To sponsor a participant or create your own supporter's page visit www.everydayhero.com.au/event/raisinghell</i>
12 December	Kurri Country Music Concert for MND <i>Concert at Kurri Workers Club featuring international recording star Wayne Horsburgh, Lindsay Butler, Shaza Leigh, Greg Bain and the Butler Boys. Contact Shirley or Steven Peters ph. 4991 5571 or sg046@australiaonline.net.au</i>

MND Cooks

We are currently looking at producing a recipe book for release during MND Week 2010. The book will be hard-bound with 100 recipes in full colour.

We would love to have contributions from members, families and supporters.

What about your favourite recipe for busy people on the go, or maybe a great recipe for those who love to indulge in some wonderful desserts?



Do the children have a recipe they love cooking for you?

How about some unique recipes for soft food with flair, or some wonderful winter soup recipes?

We need **your** recipe, a photo and several lines about why the recipe you submit is special to you.

Put that thinking cap on and help us make this a very special recipe book for members and friends alike.

Please send your recipe, photo and several lines about why the recipe is important to you to kymn@mndnsw.asn.au or by mail to MND NSW Locked Bag 5005, Gladesville NSW 1675 by **20 December 2009**.



Electric Wheelchair Appeal 2009



Help us to urgently raise funds for the purchase of two new electric wheelchairs for the MND NSW Equipment Loan Service. Donate at www.mndnsw.asn.au or MND NSW ph. 02 8877 0999.

Don't forget to order your MND NSW Christmas Cards

See the insert to this edition of *Forum* for your order form. For more information contact MND NSW ph. 8877 0999 or visit www.mndnsw.asn.au

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

Camino de Santiago de Compostella

It's amazing how many different ways our wonderful supporters choose to raise money for the Association. Judy Witherdin and Warwick Jones decided to raise funds from sponsorship by participating in the Camino de Santiago de Compostella. This event is a pilgrim's walk of 800kms from the Spanish border to the burial site of St James the Apostle at Santiago de Compostella. They walked about 30kms a day for five and a half weeks.

Here is an excerpt taken from the wonderful newsletter written by Judy and Warwick about this amazing adventure.



Even though it has been hard work, we are enjoying the countryside, villages and most of all the people. The Spanish people have treated us

with a lot of respect and we certainly don't feel like ordinary tourists but true blue peregrinos (pilgrims). They generally go out of their way to help even when we don't need it. We've also had a lot of comments on our walking poles, I think they must be the most photographed.

We have been lucky with the weather as it has been cool and generally cloudy during the day and now that we are back in high country of the high plains, the nights are cold. We have walked through the rich Navarre region, the fine wine producing La Rioja where the soils are rich red but the farmers not so rich and are now in the Castilla and Leon region which has a multitude of beautiful small villages that unfortunately are falling into disrepair due to demographic changes. It is obvious that without the money coming from pilgrims on the Camino, some of the villages would now be empty. It is noticeable that the very high standard of building that we noted in the first week is now declining. Finely cut white limestone was in abundance and every building was constructed using rock as at least on the front facade. The buildings now are a combination of brick, mud brick or pressed mud and straw. There are many old people in all the towns and villages but few teenagers. A child is born into a community and much loved by all. There is great respect for all people young and old and we always feel completely safe.

In rain, and with hundreds of other pilgrims, we walked into Santiago yesterday at the completion of the 800km Camino. We were in time to receive our Camino 'credentials' and have our details read out during the noon mass at the Santiago Cathedral. It was great, but with most things in life it is the journey, not the destination, that is important.

The generosity of our supporters is greatly appreciated.

Kerrie Cripps Memorial Trophy

The annual Kerrie Cripps Memorial Trophy Day was held at Cronulla Golf Club in May. About 175 golfers competed and the trophy, which was won by Jude Richardson, was presented by Kerrie's grandson Jayden Cripps, a budding young Cronulla golfer. Thanks

to the organisers for their efforts and also to the golfers who generously supported MND NSW through donations and the purchase of MND merchandise.



Lois Longhurst, Ladies Committee President, Jude Richardson, Jayden Cripps and Nancy Harwood, Club Vice-Captain.

City2Surf

A very big thank you to all of the brave runners and walkers who participated in this year's City2Surf and helped raise over \$19,000 for MND NSW.

**United Way**

Once again, United Way have supported our Association with funding

to purchase electric beds, communication aids and a raiser recliner armchair for our Equipment Loan Pool. This funding greatly assists us to continue to meet the varied equipment needs of our members.



Some more intrepid explorers raising funds for MND. Nicholas Merry and his girlfriend Megan at

Unsung heroes



(l-r) MND NSW volunteers, Debra Larizza and Greg Corr with Kym Nielsen, Fundraising Manager and Ayse Dalkic, Fundraising Assistant, during Volunteer Recognition Week.

Greg Corr represented the 'unsung heroes' of MND NSW at the Fundraising Institute of Australia reception, during Volunteer Recognition Week in May 2009, at Parliament House in Sydney.

Greg received a Certificate of Recognition in appreciation of the significant services provided by all the volunteers of MND NSW. This award was presented by the Honourable Kevin Greene MP, Minister for Gaming and Racing, Minister for Sport and Recreation. Debra Larizza, a previous recipient, Kym Nielsen, MND NSW Fundraising Manager, and Ayse Dalkic, Fundraising Assistant, were also present to congratulate Greg on such a special day.

The guest speaker at the event was Ian Kiernan AO, Chairman and Founder of Clean Up Australia. Ian said, "...if your dreams don't scare you....they're not big enough".

Our volunteers contribute their time and skills coordinating fundraising events, packing newsletters, preparing print publications, and assisting with day-to-day and project activities of the Association.

Their efforts make a real difference, directly and indirectly, to the lives of people living with motor neurone disease.

With this in mind, if you are thinking of becoming a volunteer or wish to hold a fundraising event, don't ponder any longer, contact MND NSW ph. 8877 0999 or email admin@mndnsw.asn.au, I would love to hear from you.

Ayse Dalkic
Fundraising Assistant

New MND merchandise

MND aluminium flashlight

Great little aluminium flashlight, handy size to carry in your handbag or pocket. Uses one AAA battery. Only \$5.

Don't be caught



in the dark!

Woof woof

They're back!!

Our great little MND puppies will be back in stock in early October and this time the litter has a gorgeous tan coat.




Get in quick before they bound out the door. Take one home for just \$5.



You can view or download your MND merchandise order form from our website at www.mndnsw.asn.au

WALK
Sydney Olympic Park


New South Wales

to d'Feet
Sunday 8 November 2009
Adults \$25
Children \$10 (5 to 16yrs)
Family \$45 (2 adults and 2 children)
Dogs \$5

For registration and sponsorship details call 1800 777 175 or www.mndnsw.asn.au

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.

Editor: Penny Waterson