



# FORUM

## Faces of the MND community

Local Griffith photographer Sue Pierce was challenged by her local photography group to find and photograph a couple who had been married for more than 50 years. She captured this portrait of MND NSW member Anto and his wife Marg who have been married for 58 years. Anto and Marg met when they were both working at a local car dealership, Marg as junior secretary and Anto as apprentice mechanic. This developed into a lifetime relationship and a family of two children – Wayne and Delia. They also have four grandchildren, two boys and two girls: Beau, Mitch, Latisha and Jana. Seeing the grandchildren grow up has been the highlight of their 58 year relationship.



Marg and Anto

In March 2012 Anto received the very first Life Member of the Committee Award from his mates at the Griffith’s Men’s Shed. Anto joined the Shed in 2006, two years before he was diagnosed with MND. He continues his involvement and Shed committee member Gordon says that Anto is a real inspiration to other members.



This beautiful photo of Emily Burrage, was taken during her family’s recent FlexiRest break at Coffs Harbour. You can find out more information about FlexiRest from your regional advisor.



David Hunter with Julie and Michael Brown on Sydney Harbour at the MND NSW Sailors with disAbilities event.



Physiotherapist Kylie Ballantyne and MND carers (left to right) Jane, Kelley and Trish at Link and Learn, Port Macquarie - March 2012.

*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.*

## Day of Hope and Remembrance 12 May 2012

The Day of Hope and Remembrance is held each year by MND NSW during MND Week. It is a time for us to come together as a community of people touched by motor neurone disease. It is a day to reflect upon the impact this disease has on people's lives and to acknowledge everyone who is a part of the MND community.

### Dedication from people living with MND by Greg Thomas

This candle is being lit in honour of people living with MND. My life has been like a road trip. For most of it on a dual carriageway, a smooth, fast and comfortable trip with beautiful scenery.

On diagnosis I moved on to a gravel road; life slowed and I had to be more cautious. Initially it was still smooth but now it is quite bumpy. I now need good suspension to make the journey manageable. Ahead I can see myself engaging 4WD where the going will be slow and tough. I get glimpses of the No Through Road sign ahead but can still enjoy the scenery

thanks to my suspension - family, friends, carers, volunteers, medical personnel and MND NSW.



22 September

*Spring Ball  
for MND  
at Rydges  
Lakeside  
Canberra*

*Karin Van  
Leeuwen ph.  
0419 694 313*

## A MonSTaR effort for MND NSW at the MonSTaR Cup 2012

Once again the MonSTaR Cup golf day has proven to be a great day. Now in its 6th year, MonSTaR Cup has become widely renowned as one of the premier golf and social events on the Sydney calendar.

This year a competitive field enjoyed the lush fairways at Pennant Hills Golf Club followed by fine food, live music and exposure to the now famous 'money can't buy' experiences which are offered for sale. MND NSW is one of several recipients of proceeds from the day. For more information see [www.monstarfoundation.com.au](http://www.monstarfoundation.com.au).



## Introducing...

**Ann McCutcheon** - Regional Advisor South Western Sydney and Illawarra

I am the new Regional Advisor for the South Western and Illawarra regions. I joined the MND Association at the beginning of March and have been busy, being orientated to the position. For the past few weeks I have participated in the Care for Carers Program held by MND NSW but I have also been gradually getting out to my region to meet you all individually. I am Irish, have a background in health, community and disability and have lived in Australia for twenty-four years. I have a dreadful sense of direction and Mr Navman is now my new best friend! For those of you I have already met, thank you for the warm welcome. I am looking forward to meeting all the other members in my area to discuss how I can best support you as your regional advisor.



## A Message from the CEO

The cold has hit, though not too hard and we are already nearly half way through 2012.

MND Week, held from 6 to 12 May, was a huge success and culminated with the Day of Hope and Remembrance on Saturday 12 May. It is always a very special day and, through remembrance and hope, we acknowledge the broad community that has been touched by MND. We had a great turnout and you can see more about the event on page 2 and read Dr Justin Yerbury's inspiring address on page 8 of this edition of *Forum*.

Media attention during MND Week was fantastic and, with thanks largely to those who volunteered to share how MND has affected their lives, we had great interest from regional and suburban papers and radio. If you would like to know where the articles appeared go to [www.mndnsw.asn.au](http://www.mndnsw.asn.au)

During MND Week the Prime Minister announced the Government's commitment to the National Disability Insurance Scheme (NDIS). Funding for the pilot sites, commencing in 2013, was included in the Budget. Thanks to all who have joined the Every Australian Counts campaign supporting NDIS. We still need your support for the NDIS because:

- there is no ongoing commitment of support past the pilot period
- the NDIS still discriminates against those over the pension age if they are diagnosed with a disability. Support needs to be based on need not age

To register your support go to the MND NSW website at [www.mndnsw.asn.au](http://www.mndnsw.asn.au) and click on the Every Australian Counts link or go directly to [www.everyaustraliancounts.com.au](http://www.everyaustraliancounts.com.au). Encourage your family and friends to register their support as well.

The most recent community to host a Walk to d'Feet MND was Tweed Heads. Almost 200 people turned up on the day and event organiser Julie McCusker had done a fantastic job in alerting the media leading up to the event. We have included some photos on page 12.

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'd like to organise a Walk to d'Feet MND in your local area contact Kym Nielsen on [kymn@mndnsw.asn.au](mailto:kymn@mndnsw.asn.au) or ph. 8877 0999.



**Canberra**  
24 June

**Port Macquarie**  
7 October

**Sydney**  
4 November

## Motor Neurone Disease Association of New South Wales

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### Equipment Service Coordinator

*Maree Hibbert*

### Equipment Assistants / Support Officer

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And...many valued volunteers including Evan and Joe volunteering during MND Week at Circular Quay



## Family Support Team

During 2012 our membership has continued to increase and this indicates that more people are hearing about the Association and our services, which is good news. However it does put some strain on our regional advisors as unfortunately our funding has not increased to help us keep up with our increased membership.

Our Sydney-based regional advisors, who each work 3 days a week, now have about 65 to 70 members in the areas they cover. At times when they are really busy they may not ring you as regularly as they would like, so it helps your regional advisor if you contact them when issues or concerns come up that you would like to discuss with them. They really do like to hear from you.

In addition to your regional advisor, the MND NSW Information Line service is provided so that you know there is always someone to talk to during business hours. Our Information Line Advisor, David Wallace, is based at the MND NSW Centre at Gladesville and you can also contact David to help with any questions or concerns, phone 1800 777 175 or 8877 0999.

One way we try to meet your needs is by educating NSW and ACT health and community care providers about MND. This is so they can learn more about MND and provide good multidisciplinary MND care through using a more coordinated approach in their local communities.

Over the next twelve months our Education and Carer Support Program Coordinator, Kristina Dodds, is travelling to various towns in rural and regional NSW, and to venues in Sydney and the ACT, to provide 4.5 hour MND training sessions for health and community care providers. These MND Aware face-to-face training sessions complement the MND Aware online training program we developed during 2011. The MND Aware project is funded and supported by Ageing, Disability and Home Care (ADHC).

### Satisfaction Surveys

Every two years MND NSW sends members a Satisfaction Survey to help us gauge how well we are meeting our members needs and to assist in future planning. We had a great response with 208 members (47% of our membership) responding to our 2012 survey. Thank you to all for taking the time to complete this.

We were glad to see that we had a good representation of members responding from both metropolitan and regional areas with just over 50% of responses from members in metropolitan areas and 45% from members in rural or regional areas (unknown 5%).

Overall satisfaction was very high with the support and services provided by MND NSW:

- 92% rated the ability of their regional advisor to offer support and information as needed as very good (73%) or good (19%)
- 100% of respondents rated the personal manner of the staff members they speak to as very good (86%) or good (14%)
- 97% rated the information pack they were sent on joining as very good (74%) or good (23%)
- 94% rated the quality of the equipment provided as very good (65%) or good (29%)

It was great to see that 97% would recommend MND NSW to others living with MND.

We also received many comments from our members indicating that they were very satisfied with the service we provide, including:

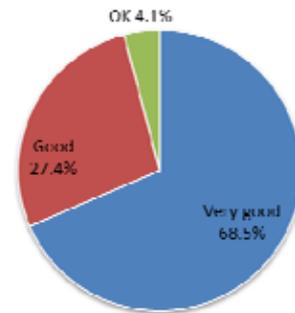
- *"The MND Association and our regional advisors have made things for us so much easier. The provision of the services and caring, happy nature of the staff is excellent."*
- *"In my opinion anyone with MND cannot do without the excellent support from MND NSW."*

People also expressed their gratitude for the equipment they received.

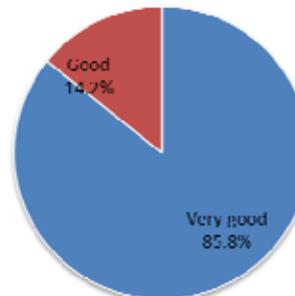
We also asked for suggestions that would help us maintain quality, improve our service, help meet the needs of people living with MND and their families and to advocate on their behalf. We have received a number of suggestions that we will look at over the coming months. The main suggestions were more home visits and face-to-face contact and also more funding for research and to raise awareness about MND.

We are happy to receive suggestions and feedback at any time so please don't hesitate to contact me about this.

**Gina Svolos**  
 Manager, Family Support



*The quality of the information and support I receive when I telephone/email MND NSW*



*The personal manner of the staff members I speak to*

*You are welcome to provide us with feedback about our services at any time. Ph. 8877 0999*

## Family Support Team (cont'd)

### Equipment

Our Equipment service staff recently reviewed the communication, computer access and environmental control devices in MND NSW Equipment Loan Pool. During this review we found that some items have been superseded and also that several items can no longer be repaired. As a result we needed to source replacement devices suitable for the needs of our members.

*From June 2012, with each loan of a communication, computer access or environmental control device, we may be asking you to complete a short evaluation form about the device and to return the form to MND NSW. Your participation will be very much appreciated and will help us make sure our Loan Pool has devices suitable for the needs of our members.*

We have been working with senior service providers from the specialist service known as TASC (Technology solutions for computer Access, Seating and Communications, Cerebral Palsy Alliance) to seek recommendations on new and replacement communication and computer access devices that may be beneficial for our members.

New devices will be purchased in the next few months and these will be made available for loan to members. As with all of our equipment items, an individual's referral for a particular device is generated by the health professional who has assessed the member and submitted the MND NSW Equipment Loan Request Form.

*Maree Hibbert - Equipment Services Coordinator*

### Update on MND Technology Survey with Sydney University

In February of this year we partnered with Master of Occupational Therapy students from Sydney University to undertake a study on how people with MND use (or don't use) technology in their everyday lives and with health and community care professionals. We had a fantastic response to the survey and we greatly appreciate your time and input. On behalf of the students, we thank you for your participation. Look out for the survey results in the September edition of *Forum*!

### Link and Learn, Port Macquarie - March 2012

MND carers from the Far North Coast and New England areas were invited to attend *Link and Learn*, a residential educational workshop held over two days and one night, in the beautiful seaside town of Port Macquarie. The aim of the two days was to link carers with each other to share ideas and information. As one participant said, "Although involved with MND for some years, I have found so much more information over the two days. Sharing with others was one of the best aspects."

Eleven of the carers at *Link and Learn* were caring for their spouse with MND, four were caring for a parent, two were caring for an adult child and one other was caring for her friend. We had a large group of seven men and eleven women. Not only were the participants there to learn but also to take some much needed 'time out' for themselves. Some of the feedback included:

- "I expected to learn about MND, services available and aids available but the linking with others has given me hope and inspiration for the future. Thank you all so much.
- I can't thank you enough for the opportunity to share with other MND carers and hear brilliant educators."

Thanks to all those who participated and opened their hearts and shared their experiences. We look forward to keeping in contact.

*Eileen O'Loghlen, Kim Sinclair and Kristina Dodds*

### Aye Aye Captain - Sailors with disAbilities - April 2012

We had a wonderful sail on Sunday 15 April cruising Sydney Harbour, thanks to our skipper Erin, and all the crew who so ably assisted us. Sailors with disAbilities was formed as a non-profit organisation to offer people with disabilities the opportunity to go sailing.

We are very fortunate that MND NSW is offered the opportunity to 'book' the yacht twice a year for a Sunday Sail, at no charge, and we usually go in autumn and spring, when the temperature is just right. Our yacht had many thoughtful adaptations such as a wide flat deck able to accommodate wheelchairs. We had 10 people on board from MND NSW and it was a beautiful day - the sun was shining, but the wind was not blowing. We did put up both sails though and it meant that we glided over the water at a slow and peaceful pace. Our first-time sailors had a fabulous day and all would love to sail again with Sailors with disAbilities.

*Put it in your diary*

*Ask the Experts*

*14 August 2012*

*at West Ryde*

## **Support Groups (cont'd)**

### **Campbelltown**

Campbelltown support group runs monthly and has been very well attended so far this year with several new members joining. We have an action packed agenda for 2012. March kicked off with Jacinta, a social worker from the area health service, speaking to the group. Jacinta spoke about the importance of linking in to palliative care team early to ensure members have access to best care, someone to assist with symptom control and enhance quality of life. Jacinta's talk raised many questions and interesting discussion amongst the group.

In April, Teresa Kemp, from the area health chronic care team spoke about breathing techniques and demonstrated different techniques to enhance breathing. Under the watchful eye of Teresa, the group practiced and gained many tips about posture and techniques to overcome issues with breathing.

I would like to take this opportunity to thank Janelle Mahoney and Kristen Peel from the Community Options at Campbelltown for their input and commitment to this group and for providing the venue. The group meets once a month on a Tuesday 10am to 12pm at 16 Warby Street Campbelltown.

**Ann McCutcheon** - Regional Advisor

### **Gladesville**

We continue to meet at Gladesville on the first Wednesday of the month on alternate months. During our last two meetings we have had some interesting discussions following the showing of the Ask the Experts sessions from the International Symposium held in Sydney last year.

Our next meetings are on 1 August and then 3 October. Everyone is welcome to attend – please let me know if you would like your name added to the invitation list.

**Caroline Gleig** - Regional Advisor.

### **Newcastle and Hunter**

Join regional advisors Eileen and Kim at the Newcastle MND Support Group meetings, where they run two support groups at the same time and place: a carers support group and a members support group. Each group is facilitated by either Eileen or Kim and meets on the third Wednesday every second month.

These groups provide you with the opportunity to meet other members, their family and friends in a relaxed informal environment and to provide support, information and to share ideas.

Future meetings are at the new venue in Charlestown Multi Purpose Centre, 17 James Street Charlestown. The next meeting will be held

at Charlestown on Wednesday 20 June from 12.30pm until 2.30pm and light refreshments will be provided.

For more details contact Eileen O'Loughlen 4921 4157 or Kim Sinclair 4985 5022

**Eileen O'Loughlen and Kim Sinclair** - Regional Advisors

### **Northern Beaches**

Our meetings continue to be held at the Palliative Care Cottage at Mona Vale Hospital. Each meeting has a different theme and covers important aspects of MND care. So far this year our guest speakers have updated us about the National Disability Insurance Scheme and increased our knowledge about managing oral secretions and swallowing difficulties.

Meetings are held every two months from 11.30am and finish at 1.30pm. Free parking is available directly outside the building. Please remember to pick up a parking voucher from Sue at the reception desk of the Palliative Care Cottage and display it near your front windscreen. Our next meeting is on 17 July and we look forward to catching up with you there.

**Jo Fowler** - Regional Advisor

### **Liverpool**

This is a new group which started at the end of last year so it is gradually gaining momentum with more people joining. In March, Kylie Hasham, Speech Pathologist, Liverpool Hospital, discussed issues related to swallowing and communication due to MND. Kylie made some great suggestions and the group tasted various products on the market. Everyone talked about what works for them and also about other strategies that may not have been so successful. Support groups are a great way to share information and learn from each other.

In April, Felicity, a dietitian from Liverpool Hospital, spoke to the group about the importance of a good diet to enhance wellbeing. Felicity addressed the issues for people who have swallowing difficulties and the different options available to them and the groups asked many questions and shared tips.

The Liverpool Support Group meets monthly on a Monday 10.30am to 12.30pm at the Thomas Moore Education Centre at Liverpool Hospital. If you need assistance with transport or information about parking contact Marina Jurman, Social Worker, Liverpool Hospital on 9828 4782. I would like to thank Marina Jurman and Diana Kelecevic for their enthusiasm and support in running this group.

**Ann McCutcheon** - Regional Advisor

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*Support group dates for 2012 are available at [www.mndnsw.asn.au](http://www.mndnsw.asn.au)*

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## Ask the Experts

**14 August 2012**  
at West Ryde

**Come and quiz the experts.** Ask the Experts forum is a popular day when you, family members, carers and friends can bring your questions about MND and have them answered.

Our experts will speak about MND, what's new in MND research, stem cells and unproven therapies.

For those who are shy about talking in public, have speech difficulties or have a query you would rather have someone else ask, you can pass your question onto any MND NSW staff member and they will ask the question(s) on your behalf. Remember your question may be just the one others want to ask!

Ask the Experts will take place in the Ryedale Room at Ryde-Eastwood Leagues Club, West Ryde, from (arrive at 10am) 10.30am to 3.15pm, Registration is free and includes morning tea, lunch and afternoon tea but **you must RSVP by Wednesday 8 August to attend.** Put the date in your diary now!

For more information or to book contact MND NSW ph. 02 8877 0999 or 1800 777 175 or email [familysupport@mndnsw.asn.au](mailto:familysupport@mndnsw.asn.au)

Recipes for people with swallowing difficulties

*New 2012 edition available free for members.*

*MND NSW Infoline 1800 777 175*

## Family Support Calendar

<b>19 Jun</b>	<b>Information Evening for people recently diagnosed with MND, their family and friends</b>   <i>Gladesville</i>
<b>14 Aug</b>	<b>Ask the Experts</b>   <i>West Ryde</i>   You, family members, carers and friends can bring your questions about MND and have them answered
<b>21 Aug</b>	<b>Information Evening for people recently diagnosed with MND, their family and friends</b>   <i>Gladesville</i>
<b>17 Sep</b>	<b>Lunch for bereaved carers</b>   <i>Gladesville</i>   For those who have experienced a bereavement through MND in the past twelve months
<b>16 Oct</b>	<b>Information Evening for people recently diagnosed with MND, their family and friends</b>   <i>Gladesville</i>
<b>22 and 29 Oct</b>	<b>Learn Now Live Well</b>   <i>Gladesville</i>   For people with MND, their family and friends. Two day educational program covering living well with MND and services available for people living with MND
<b>24 Nov</b>	<b>Christmas Party for family support members, their family and friends</b>   <i>West Ryde</i>
<b>11 Dec</b>	<b>Information Evening for people recently diagnosed with MND, their family and friends</b>   <i>Gladesville</i>

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.*

## Support Groups

**METROPOLITAN** Contact MND NSW ph. 1800 777 175 for more information

*Campbelltown - Ann McCutcheon | 1800 777 175 | [annm@mndnsw.asn.au](mailto:annm@mndnsw.asn.au)*

*Gladesville - Caroline Gleig | [carolineg@mndnsw.asn.au](mailto:carolineg@mndnsw.asn.au)*

*Liverpool - Ann McCutcheon | [annm@mndnsw.asn.au](mailto:annm@mndnsw.asn.au)*

*Northern Beaches (Mona Vale) and Northern Sydney (Hornsby) - Jo Fowler | [josephinef@mndnsw.asn.au](mailto:josephinef@mndnsw.asn.au)*

*Western Sydney - Jenny Judd | [jennyj@mndnsw.asn.au](mailto:jennyj@mndnsw.asn.au)*

### REGIONAL AND RURAL

*ACT and Southern NSW - Gail Ferguson | 6286 9900 | [gailf@mndnsw.asn.au](mailto:gailf@mndnsw.asn.au)*

*Central Coast - Audree Dash | 4384 2907 or Jo Fowler | 1800 777 175 | [josephinef@mndnsw.asn.au](mailto:josephinef@mndnsw.asn.au)*

*Central West - Jenny Judd | 1800 777 175 | [jennyj@mndnsw.asn.au](mailto:jennyj@mndnsw.asn.au)*

*Illawarra - Ann McCutcheon | 1800 777 175 | [annm@mndnsw.asn.au](mailto:annm@mndnsw.asn.au)*

*Muswellbrook (Upper Hunter) - Kim Sinclair | 4985 5022 | [kims@mndnsw.asn.au](mailto:kims@mndnsw.asn.au)*

*Newcastle and Hunter - Eileen O'Loughlen | 4921 4157 | [eileeno@mndnsw.asn.au](mailto:eileeno@mndnsw.asn.au) or  
Kim Sinclair | 4985 5022 | [kims@mndnsw.asn.au](mailto:kims@mndnsw.asn.au)*

*North West (Tamworth) - Kim Sinclair | 4985 5022 | [kims@mndnsw.asn.au](mailto:kims@mndnsw.asn.au)*

*Port Macquarie - Eileen O'Loughlen | 4921 4157 | [eileeno@mndnsw.asn.au](mailto:eileeno@mndnsw.asn.au)*

*Gold Coast Carers - Chris Carroll | 0421 252 455 | [chrisc@mndnsw.asn.au](mailto:chrisc@mndnsw.asn.au)*

## Day of Hope and Remembrance 2012



*Dr Justin Yerbury, our guest speaker at the 2012 Day of Hope and Remembrance is a Bill Gole Postdoctoral Research Fellow at the Illawarra Health and Medical Research Institute.*

*Justin grew up in the suburb of Oak Flats in the Illawarra region.*

### A Tale of Two Hopes

Dr Justin Yerbury

First of all I would like to thank the MND Association for the invitation to talk to you today and for all the support I have received from them over the years. I have a long history with the Association in many different capacities. It is a real honour for me to be here today to speak to you as we all remember the lives of those we have lost and live in hope for the future.

For those of you whom I have not had the pleasure of meeting, my name is Justin Yerbury and I am a medical researcher based at the Illawarra Health and Medical Research Institute at the University of Wollongong. But that is not the only thing that defines me, I am a husband, a father, a brother and a friend and I too have been touched by motor neurone disease. It has been a long time since I first found out what MND is – and like many of you here today I had to find out the hard way. Eighteen years ago my uncle was diagnosed with MND and it didn't take long to figure out that this terrible disease was being inherited within members of our family. Since then I have lost some of the people most dear to me including my mother and little sister.

I have been asked to talk to you about HOPE, with which I have had my ups and downs with over the years. The first thing I did when I asked to talk to you about hope was to reflect on what hope meant to me – but I found it was such an abstract concept I needed some help. So I did what everyone does these days, I googled it. With the help of Google it became clearer to me that I have experienced two kinds of hopes.

Hope can be a verb (or doing word) as in "I hope that today will be warm" or "I hope I get an iPod for Christmas" or it can be a noun as in "live in hope" or "don't give up hope".

What I wanted to do today was to give you an idea of how these two kinds of hope have made me who I am and perhaps give a little hope along the way.

When I first found out about MND it was such a mystery to me, and all of my family. I worked with my parents at their Australia post outlet, and I played a lot of basketball – I had no medical or scientific knowledge whatsoever. None of us did, so it made it difficult for us to understand what was happening. It also appeared to me that MND was a mystery to doctors and researchers. We could only sit and hope for a cure.

This was one of those life changing moments... it was the moment when a hope changed my life.

The kind of hope that changed the path my life was travelling down was the doing word or verb. I hoped for a cure. But to me this hope, the verb, the doing word was "not doing" but waiting. It was a flat and lonely hope that seemed to have no chance of coming true.

In my naïveté I thought that if everyone just sat around and just hoped for a cure this would not get us any closer to understanding this disease let alone finding a cure. BUT in fact, MND research was really taking off in the mid 1990s due to the discovery of the first known cause of MND – mutations in SOD1 gene.

So rather than hope for a cure I set about going back to university and trying to increase my knowledge of biological sciences so I could understand what MND was and how it worked. I had never studied biology before and was generally a go with the flow kind of person, but in this case it was my inability to sit back and "hope" that turned my life around and pointed me in a new direction. I am now a research fellow at the University of Wollongong and run my own research group trying to understand the molecular mechanisms that make MND tick. I have come a long way, it has been 13 years since I went and enrolled in a university course to try to better understand what MND was.

The fact is I am still trying to understand what MND is and how it works – just at a more

*(Continued on page 9)*

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*You can find out more about the researchers funded by MND Research Institute of Australia at [www.mndaust.asn.au](http://www.mndaust.asn.au)*

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## Noticeboard (cont'd)

*(Continued from page 8)*

detailed level than I could have ever imagined.

Throughout these years of study we as a family have had more than our fair share of tragedy, from our immediate family we lost my sister and my mother in the last 10 years to MND. This has made it a very difficult journey, but one I am only more determined take on and to make a difference to.

**T**he second hope I wanted to talk to you about is the noun, noun being the name of a thing or place. This kind of hope is a feeling, a feeling that what is wanted can be achieved or the feeling that things will turn out ok. We have all had to cope with our own story but I know that being able to live in hope has been a big part of my life. At times it is hard, but I have an amazing family and bunch of friends that can turn me back around if needed.

So this kind of hope has been important in my life, because it is that glimmer of hope, that feeling that things could change have allowed me to never give up.

**I**n the last two years I have achieved my first goal – which was to be able to research directly in to MND. This has been a long term goal and took 10 years of study. So I am now standing at the start of a new road and I have hope that this one will also lead me to where I want to go.

In the lab we are trying to determine how MND progresses from one part of the nervous system to another. We know that the neurons contain protein junk piles and we think that these are somehow involved in progression of disease. The idea is that if we can figure out how the disease moves we can design a way to stop it in its tracks.

**I**wanted to also pass on some of the hope that I see in research to you here today. I have been able to start a research group with a bunch of students and a research assistant and we are chipping away and making small steps towards our goals. But we are just a small part of the MND research community from all around the world.

I liken MND research to a snowball – and hopefully I can consider myself, and my group, a small patch of snow picked up along the way as we grow bigger and move faster. Each experiment we, and others, do contributes to this snowball gaining weight and picking up speed. Racing towards a cure for MND.

To give you an idea of how much speed we are picking up you have to consider that MND was first described over 140 years ago, and it was about 120 years later that the first known cause of MND was discovered. It took another 10 years before we discovered the next MND gene, but in the last 3 years we have discovered another 8 MND genes. This is moving so fast that by next year it is likely that we will know ALL of the genes that cause familial versions of MND. Putting the familial MND geneticists out of a job. Importantly, these genes can also tell us about those cases of MND which are not inherited – for example we now know that one of the MND genes called TDP-43 is important in all sporadic cases of MND.

**S**o we are now so close to having most of the pieces of the puzzle and we need to get to work and starting putting the puzzle together. Our prospects for having a cure for this terrible disease is picking up speed every day – this is the hope that I want to pass on. That some of the brightest minds around the world are working on this every minute of every day working towards the same goal.

Hope is such an important thing for our MND community. It plays an enormous role in giving people strength to fight this insidious disease. Our symbol for hope is the blue cornflower which appears fragile but is actually quite hardy. And I think that the motto for the MND Association – Never Give Up – is a fitting description of our story and fight against MND. And I must say the staff and volunteers at the MND Association (all the various branches) do a fantastic job of inspiring that in us.

So that is my story and how two kinds of hope have shaped how I live and how I have arrived where I am today. I hope that my story has in some way given you some hope that we are quickly moving towards a time when we have a cure for MND.

Thank you.



Write to the  
Editor of  
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Locked Bag  
5005  
Gladesville  
1675 or email  
info@mndnsw.  
asn.au

## Noticeboard



**Plenary Session III: The Biology of ALS and the Significance of Chromosome 9**

Have you ever found yourself asking 'what does that mean' after reading an article about the latest discovery in ALS research? You're not alone! This video from the 2012 USA National ALS Advocacy Day and Public Policy Conference provides you with the basics in the biology of ALS/MND, with a particular focus on the significance of chromosome 9. About 52mins at <http://livestre.am/37Nx4>



**Apple Disability Apps for iPhone and iPad**

Apple is introducing a growing number of apps catering to individuals with special needs with a featured section in its App Store. The 'Special Education' section includes 72 applications for the iPhone and 13 applications for the iPad in 10 categories ranging from communication to emotional development and life skills. Source: National Disability Services May 2012



**Qantas Carer Concession**  
The Qantas Carer Concession Card is

issued to people with a disability and high level support needs who require the full-time assistance of a carer whilst they are on the plane. For more information visit [www.nican.com.au/about/qantas-carer-concession](http://www.nican.com.au/about/qantas-carer-concession). Source: Nican and Physical Disability Australia Ltd

**For sale - wheelchair converted car**

2004 Holden Commodore Y11 Executive Station Wagon (Olive Green metallic) 140,000kms. Vehicle has been well cared for and is fitted with a swivel base Carony 12inch wheelchair by AutoAdapt. Registered to Nov 2012. Vehicle is valued at \$6,000-\$6,500 and wheelchair is valued at \$6,000, however I am willing to sell the car for \$9,500 and I am open to offers. For more information contact Jenny ph. 0401 027 716 or 6628 4435.



*Are you thinking about organising a community fundraising event for MND? Speak with Kym Nielsen ph. 8877 0912 about your plans*

## WHY ANYONE?

*I often wondered why John, the girls and I, never asked the questions; "Why John, why us, why our family"?*

*It was only looking back that I understood that with motor neurone disease the question is "Why anyone"?*

*Sadly I know from our journey with MND, (October 1996 to February 1999) that the courageous, inspirational spirits living with MND, and their families, need special care. They also need hope for the future through research that will develop treatments and find a triumphant cure. I also know we would all do anything to prevent precious people dear to us from finding themselves locked into the relentless journey dictated by the progress of MND.*

*There are important ways we can all help turn the tide on motor neurone disease. We can keep in touch with our unique MND Family by getting together and supporting one another. We can also consider making a bequest in our Will to benefit MND NSW care, support and research.*

*Like each drop of rain in our water catchments, each contribution to MND NSW makes an impact.*

*WE can indeed MAKE A DIFFERENCE! Please join our growing group of donors. Take care, we care!*

~ Pamela J Hennessy

To honour John and the hundreds of people living with MND in NSW each and every day we ask you to make a difference.

Where there's a Will, there's a way! Leaving MND NSW a gift in your Will can make all the difference to people living with motor neurone disease. Your valuable gift will form a key part of the Association's long-term income and help us to continue providing essential equipment, information, support and advice for people living with MND, their families and carers and help fund research.

Make a world of difference to someone living with MND and be remembered for something incredible!

For more information about leaving a gift to MND NSW in your Will, please contact David Dubin Ph. 02 8877 0999, Freecall 1800 777 175 (NSW only) or mobile 0431 525 372 for a confidential discussion.

Alternatively, David can be reached via email at: [DavidD@mndnsw.asn.au](mailto:DavidD@mndnsw.asn.au).

## Community events

Another MND Week has come and gone with outstanding support again from our wonderful volunteers. Puppies were the overwhelming choice for sales this year with over 2,000 puppies sold. Merchandise was sold at railway stations, shopping centres and corporate offices raising over \$27,000 in sales and donations. Thank you to everyone who worked so tirelessly to make MND Week 2012 a great MND Week.

*Kym Nielsen, Fundraising Manager*

### Cornflower Blue Day 2012 @ Parramatta Station

Our group of three - Adam Lord, Jeffrey Lord and Benn McNally volunteered for our first time this year. We manned the fundraising table at Parramatta train station; catching the early morning commuters on their way to work and a few tired shift workers heading the other way. We

received an amazing reception from the commuters of Parramatta, with the arrival of every train bringing dozens of people interested to know more about our fundraising for MND.

We raised a total of \$913 for the day which we were really proud of, but more importantly we informed hundreds of people of the effect of MND on every day people like you and me. It was amazing to see the immediate response people had when we spoke about MND – It is incredibly reassuring to see such humanity in what can sometimes be a pretty cruel world...

*Benn McNally*



*Thank you to all of the volunteer event organisers for their hard work in organising great events for MND*

### Sydney half marathon - thanks Prue

(pictured from left, Shane Halliday, Ethan Halliday (baby), Prue Burgun, Alannah Halliday and Kay Halliday)



Our friend, Prue, ran the Sydney half marathon on Sunday 20 May. Prue raised over \$4500 for MND in sponsorship in honour of my father-in-law, Owen "Jeff" Halliday, who lost his battle with MND (familial) on 1 December 2011. We are so proud of her for raising not only funds but also awareness of MND and wanted to share her good work.

*Debbie Halliday*

### Kilimanjaro trek

The trek was six days and 100kms. We walked from 7-8am till 4pm each day, except on summit day when we arrived at camp at 5pm, had dinner then slept (or tried to) till 11pm and started hiking at midnight to reach the summit at 6.30am in time for sunrise. This was HARD!! But knowing we were doing it for a great cause made it a whole lot easier, when I wanted to give up I just thought of mum and she kept me going (I lost mum - Laraine Hunter to MND in Jan 2009). We were only able to stay on the summit for 10min because it was so cold, around -18deg. Then the 2-day long walk back down for a well-deserved shower! We raised \$5877 - when we started we were hoping to raise \$2000 so were amazed and honoured by the support we received from family and friends.



*Lisa Hunter and Erin Avery*

### Chamber Developments Charity Golf Day Raises \$6,450 for the Motor Neurone Disease Association



The Camden Lakeside Country Club was the venue for the annual Chamber Developments Charity Golf Day, this year in support of the Motor Neurone Disease Association of NSW.

131 players participated in the round of golf and each player was "partnered" with a player of the US Masters Open, which finished on the morning of the Charity Golf Day, to determine the winning score.

Players gathered at the Camden Lakeside clubhouse early on the morning of 9 April to watch the end of the US Masters on the big screen while enjoying a scrumptious breakfast, before heading out to the course for a Stableford golf competition.

Back in the clubhouse, the players enjoyed lunch while being entertained by renown Sydney comedic magician Jack Black, who also helped inspire enthusiasm for various raffles and auctions.

Our appreciation goes to the major sponsors Pure Projects of Milsons Point, Project Surveyors of Macquarie Park and BHI Architects of Kiama.

Thanks also go to our prize sponsors Wests League Club, Masters Home Improvements and Phillip Lodge Ashfield.

The Directors of Chamber Developments are proud to be able to raise this donation for the MND Association and hope that it assists to continue their invaluable work.

*Brian Brown*

## Walking to d'Feet MND in Tweed - May 2012

Sunday 20 May saw the inaugural Walk to d'Feet MND in the Tweed Heads area. The Walk was instigated by member Julie McCusker who rallied lots of local support.

The weather was gorgeous as was the venue for the Walk. What a wonderful atmosphere.

Loads of families and friends Walked to d'Feet MND and then settled back to listen to some lovely music by Roger Munsie and friends.

The Tweed Heads Coolangatta Lions Club organised a sausage sizzle to ensure that no one went hungry.

A big thank you to Julie for all of her hard work and what an inspiration you are to us all. Thank you also to the Gold Coast support group for your assistance on the day.



Contact MND NSW now for your *Drink Tea for MND* information pack and registration form  
 ph. 8877 0999  
 or email [fundraising@mdnsw.asn.au](mailto:fundraising@mdnsw.asn.au)

### Dates for the Diary

19 Jun	<b>Killara Golf Club Charity Golf Day</b>   Killara   Ann Vince Kerama@bigpond.net.au
23 Jun	<b>Champers &amp; Pampers</b>   Cardiff South   Heidi Smith divinebeauty@live.com.au
24 Jun	<b>Walk to d'Feet MND - Canberra</b>   Kym Nielsen, MND NSW ph. 8877 0999
2 Aug	<b>Killara Bowlers Ladies Bridge Day</b>   Killara Golf Club   Diana Francis at Killara Golf Club ph. 9498 2700
18 Sep	<b>Drummond Charity Golf Day - Canberra</b>   Gold Creek Country Club   Rodney Laughler fyshwick@drummondgolf.com
22 Sep	<b>Spring Ball</b>   Rydges Lakeside Canberra   Karin Van Leeuwen ph. 0419 694 313
29-30 Sep	<b>Open Garden</b>   17 Linden Ave Pymble - call for volunteers to assist with refreshments   ph. MND NSW 8877 0999
7 Oct	<b>Walk to d'Feet MND - Port Macquarie</b>   Bev Smith ph. 0411 335 104 or 6583 8345, or Kym Nielsen, MND NSW ph. 8877 0999
19 Oct	<b>McGrath Wollongong Golf Day</b>   Wollongong Golf Club   Bryan Wells BryanWells@mcgrath.com.au
28 Oct	<b>Burgh to Beach 8-10km Fun Run</b>   Helensburgh to Stanwell Park   Nathan Johnston nathj85@bigpond.com
4 Nov	<b>Walk to d'Feet MND - Sydney</b>   Kym Nielsen, MND NSW ph. 8877 0999

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**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*