

The Cornflower



SUMMER ISSUE 2014/15

Carers come together
to conquer the
Story Bridge



New Patron for MNDQA • MND Conference Wrap • Key events for 2015

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Our Team

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Motor Neurone Disease Association of Queensland

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Feedback and contributions

You can send your feedback and story ideas to fundraising@mndaq.org.au

A message from our CEO

Ladies and gentlemen

I'm pleased to be able to say that 2014 was great year for MND Queensland.

A highlight for me was the seventh Bi-Annual National MND Conference. The event was held on the Gold Coast in October and was well attended by the local MND community, which is always great to see. The calibre of speakers was fantastic and the event culminated in an Ice Bucket Challenge supported by all presenters. Events like this really enhance our knowledge and understanding of MND – particularly the research and innovations that are being explored. If you're interested to learn more about the conference, please refer to the story on page four.

In 2014 we appointed new Board members, which resulted in a stronger, more diverse group who are focused on the diligent governance of the organisation. In October Dr Amanda Pavey joined MND Queensland, and we are very fortunate to have such a well-credentialed and dedicated Regional Advisor who is committed to reconnecting with all MND clients. We have also recently been in discussions with MND and Me about the opportunity to work together to better support the MND community in Queensland. With all that in place, 2015 is set to be another busy but exciting time for our organisation.

Thank you to everyone who provided feedback on our communications survey (either online or in writing) – we had a positive response rate and your contributions are now being encompassed into our strategic communications plan for 2015, which you will see come to fruition in the new year.

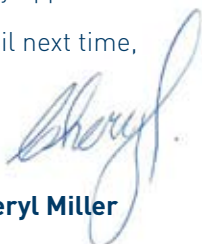
My focus for 2015 will remain on three key priorities: taking a more strategic approach to our marketing, communications and fundraising activities; developing mutually-beneficial partnerships that will increase our income generation; and continuing to connect with our clients and increase our engagement with the MND community.

Having the backing of an experienced Board and passionate team always go a long way to helping a CEO to achieve their goals, and I am very fortunate to have that support. I'd like to thank our Chair Peter Denham, the members of the MNDQA Board and my team for all of their contributions throughout 2014 – never underestimate your value to the organisation and most importantly, to our members, clients and donors.

As we do every year in 2014 we are running our end-of-year donation appeal. The money we receive from your donations enables us to continue to provide our much-needed services, equipment and support to our members and clients, so please give generously.

On a final note, I would like to acknowledge the generous contributions provided to MNDQA by the John Villiers Trust, the Walter and Eliza Hall Trust, the Ford Burnett Foundation as well as the ongoing funding provided by the Queensland state government. I would also like to thank all of our support group convenors, carers, members and supporters who work tirelessly to help those affected by MND, whether that be providing care, hosting events, fundraising or donations, your efforts are truly appreciated.

Until next time,



Cheryl Miller

Chief Executive Officer



Governor of Queensland accepts Patronage of MND Queensland

His Excellency the Honourable Paul de Jersey AC, Governor of Queensland accepted patronage of MND Australia in September 2014.

Paul de Jersey was born in Brisbane and graduated in Arts and Laws (Honours) from the University of Queensland. He was called to the Bar at the end of 1971 and was appointed as Her Majesty's Counsel (QC) in 1981. He was appointed as a Judge of the Supreme Court of Queensland, became 17th Chief Justice of Queensland and served in that role until July 2014.

Beyond the court, His Excellency has been extensively involved in community and charitable endeavours, especially in Queensland. He served as Chairman of the Queensland Cancer Fund (1994-2001), President of the Australian Cancer Society (1998-2001), and a Trustee of the National Breast Cancer Foundation (1994-1999). His Excellency chaired the Council of QIMR Berghofer Medical Research Institute, Queensland's leading and signature medical research institute, from June 2013 until his appointment as Governor of Queensland on 29 July 2014. In recognition of his contribution to the Australian community, the Governor was appointed a Companion of the Order of Australia in 2000, and awarded a Centenary Medal in 2003. He holds honorary doctorates from the University of Queensland, the University of Southern Queensland and Griffith University.

The Governor lends support as vice-regal patron to a wide range of community groups during his term in office. Patron organisations are generally Queensland-based community groups and the Governor only accepts patronage according to rigorous criteria.

Persistence pays off with Centrelink

In October 2014, MND Queensland's Client Service Advisor Denise Plunkett-Mansell was invited to speak to staff and key-decision makers at the Department of Human Services (Centrelink) in Brisbane about MND client needs, specifically relating to their ability to work or to gain access to a Disability Support Pension.

This was the culmination of five years of persistence and hard work by Denise who was receiving daily calls from distressed and frustrated clients who had been turned away by Centrelink. Motor neurone disease had not been explicitly listed on Centrelink's list of 'acceptable' diseases, despite recognising ALS. This meant that when clients and their carers sought assistance from Centrelink they would be refused on the basis that MND was not listed.

Denise said she spent a lot of time trying to convince Centrelink social workers to enable assistance for MND clients and had made numerous offers to work with them and to educate them about the condition and the needs of those affected by MND. The Department of Human Services finally accepted Denise's offer and invited her to speak at a Staff Development Day in October.

"I was faced with a room of about 100 allied health professionals, nurses and some doctors, who were eager to learn all they could about MND. I spoke about the issues related to the disease's process and how quickly it changes and degenerates, the time frame from diagnoses, and some of the many variable issues associated with MND," said Denise.

The department has been provided with resources relating to the latest information about MND and how to access up-to-date education to ensure they can support MND clients, and Denise is confident the attendees now have a better understanding of the condition.

"I was able to tackle the issue [with Centrelink] from a client and carer's perspective. It is so important that we provide backup for the carers and that we work to ensure all MND clients get immediate and equitable care. I hope this is the first of many opportunities to provide a more educated and realistic view to all government departments that deal with our clients," Denise said.

Carers conquer the Story Bridge

Carers and supporters from the MND, Huntington's and Autism communities came together during Carers Week in October to conquer the Story Bridge as part of the Bridge2Care event.

Bridge2Care was created to raise the awareness of the role of carers and to celebrate their contributions. The event started in Sydney in 2012, where supporters braved the Harbour Bridge, this was the first time the event was run in Brisbane. Event organisers said, "Carers are just like bridges – the nurturing connection, always there when support is required."

There are 2.7 million carers across Australia who provide unpaid care and support to family members and friends with a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue, or who are frail aged.

Carers Week is a time to acknowledge and celebrate unpaid carers and the diversity of caring roles being performed. In 2014, the focus was - 'Take a Break, Raise Your Voice and Support our carers'.

We are very proud of all of the amazing carers in the MND community, and would like to take this opportunity to thank you all for your enormous contribution.



During Carers Week, MND Queensland was awarded a certificate of appreciation, which recognised our provision of service and support in the community. The award was accepted on behalf of MNDQA by Dr Amanda Pavey and Denise Plunkett-Mansell who attended the award ceremony.

2014 National MND Conference Wrap

The seventh Bi-Annual National MND Conference was held on the Gold Coast in September. The event was open to allied health care professionals and members and staff from the MND community. This year's theme focused on three key areas:

- 1 **Participation:** Models of support for people with MND, education and information, and carer support.
- 2 **Partnerships:** Frameworks and pathways of interdisciplinary care, working at the interface and collaborative approaches to care.
- 3 **Progress:** Advances in knowledge and clinical care, the National Disability Insurance Scheme, technology and cognitive change.

There was an impressive line-up of speakers at the conference, some of the highlights included:

- A touching and inspiring keynote address delivered by our Board member Ray Currie, who shared his personal account of losing his wife Sue to MND.
- Dr Rob Henderson, Neurologist at the Royal Brisbane Women's Hospital, provided insightful information into the 13 key genes now identified as being related to MND and discussed the relevance of the discovery of the C9ORF72 gene and the overlap with frontal temporal dementia.
- Dr David Oliver, a Palliative Care Specialist from the United Kingdom, spoke about the dynamic and progressive changes of MND, and the importance of advanced care planning to enable a person with MND to be able to express their wishes on their future care. Dr Oliver's research indicates that more than 50 per cent of people suffer cognitive change, which is a huge increase on previous figures, which suggested the number was less than 10 per cent.
- Shyuan Ngo, from the Motor Neurone Disease Research Institute of Australia (and Post Doctoral Fellow from the University of Queensland), shared some of her research involving genetics, metabolism, the environment and biomarkers.
- Industrial Design Engineer, Heath Reed, and his team of product designers and researchers from Sheffield Hallam University, showcased a brace collar (cervical orthosis) that they are developing to better support neck muscle weakness due to a neurological disease.
- Professor Samar Aoun, from Curtin University, spoke about a new assessment tool, which was piloted in Western Australia, designed to ascertain and assess carer support needs.
- Carmen Sanchez, a consulting nurse, presented the **'So Talk'** single-communication, multi-lingual app, which she developed to assist MND patients to continue speaking. The app will be available to purchase with all proceeds from the sale going to MND and MSA charities.
- Registered care manager Lindy Mills talked about the challenges of providing optimal care to MND patients living in remote areas and/or at a great distance from acute care settings.
- Paul Talman provided an update on the Australian Motor Neurone Disease Register, which is a national registry for clinical MND patient information. To date there are close to 2000 patients registered and the information helps to provide data, which can be used to improve patient care through continuous evaluations and to help identify treatment gaps.
- There were also various other presentations including, non-invasive ventilation and gastrostomy tubes, common-sense approaches to community care, and the importance of involving occupational therapists in helping MND clients to manage their condition.

Monique pushes hard for her Dad

In honour of fathers - past and present – Monique Palomba signed up to complete the 10-kilometre Bridge to Brisbane fundraising event. Not an easy feat in itself, Monique was teamed up with her father Joseph who suffers from MND and is wheelchair bound.

She was committed to enduring the challenge of pushing Joseph, who weighs close to 90 kilograms, in a wheelchair for the entirety of the 10-kilometre course.

Monique said, “Dad can barely walk 10 metres now let alone 10 kilometres. I wanted to do the challenge for him.”

Monique had been participating in the event since 2006 and has always been an active runner. In preparation for the event she was running two to three times a week, two months prior to the event, which included a test run with Joseph.

“At the time, I remember thinking I hope my dad can hold on because it’s going to be a bumpy ride, and Lord help me if I lose him on the downslope of the bridge,” said Monique.

Fortunately Monique and Joseph successfully completed the event together in September. As anticipated, it proved a very tough exercise but the pair made it through unscathed in a time of 1 hour and 43 minutes and raised \$1,364 for MND Queensland.

Monique described it like pushing a lopsided, over-filled shopping trolley with the handles of a wheelbarrow affixed at one metre high.

“Try pushing that over the Gateway Bridge – a 2.2 kilometre stretch alone - then along a very uneven road on Kingsford Smith Drive, up and around the Inner City Bypass (another nasty incline) and through to the RNA Showgrounds to reach the finish line. That was me pushing my dad in his wheelchair,” she said.

For Monique, in spite of the physical discomfort of running with her dad, emotionally, it was such a proud moment. “No matter how much exhaustion I felt I was never going to give up – on the race, or on my dad.”



“No matter how much exhaustion I felt I was never going to give up – on the race, or on my dad.”

Client services update

At the end of each year, I always find myself reflecting on the year and how quickly time flies, and 2014 had many ups and downs. Michael Stasior said, *'You must motivate yourself every day'*, this is something that I feel is so pertinent to working with people living with the horrendous disease that is MND.

In 2014, we welcomed our new CEO Cheryl Miller whose enthusiasm and experience in the not-for-profit sector has greatly benefited us. She keeps us on our toes and has quickly made it her mission to become truly ingrained in the MND community. This was evident in February when Cheryl single-handedly pulled together the state conference, and we were honoured to have Governor (at the time) Penelope Wensley give the inaugural Charles Graham oration. Shirley Graham, who co-founded MNDAQ gave a gracious reply, which was as inspiring as the Governor's speech.

Throughout the year, we provided ongoing support to carers and families, as well as education to health care professionals. A highlight for me was getting the opportunity to educate and engage with staff at Centrelink about better supporting our MND clients.

Several fundraising events were held in 2014, including the Shades of Blue morning tea hosted by the Friends of MND group. In May we held the MND Walk to D-Feet event, which was a great success and was supported by many wonderful volunteers. I was honoured to be asked to lead the walk and was accompanied by a long-time client, James, who attended the event with his carer. James enjoyed the night but sadly lost his battle a few weeks later – just goes to show how special these events can be.

So as you can appreciate, it's been another busy but fulfilling year, which will no doubt continue into 2015. I encourage you to take time to also reflect on your year - stop, smile and just smell the roses so to speak. I'll leave you with a lovely quote from Helen Keller, *'The best and most beautiful things in the world cannot be seen or even touched, they must be felt with the heart.'* Here's to a great 2015!

- Denise Plunkett-Mansell

Regional Advisor services to be further strengthened

In addition to the appointment of Dr Amanda Pavey, and to support the work she's commenced in reconnecting with all MND clients, we have expanded our Regional Advisor services to better support regional areas in Queensland. In 2015, we welcome Sharon Gray to the MNDAQ team. Sharon has been appointed as Regional Advisor, North Queensland and will be based in Townsville. Far North Queensland has not previously had the support of a locally-based Regional Advisor and Sharon will be available for MND clients in Townsville, Cairns and when required, for clients as far south as Sarina. We are also in the process of appointing another Regional Advisor, based in Brisbane, who will assist Dr Pavey and provide support in the Brisbane and on the Gold Coast and Sunshine Coast. These additional roles have been funded largely by money raised from the Ice Bucket Challenges, which illustrate the importance of backing MND fundraising initiatives, and will go a long way to strengthening our services and ensuring we can provide the immediate assistance and support that is so critical to our clients.

Professor Kiernan takes on the role of Chairman

Professor Matthew Kiernan was elected as Chairman of the MND Australia Research Committee, taking over the role from Professor Dominic Rowe who was Chairman from 2004 to 2014. Professor Kiernan's impressive resume includes; Bushell Chair of Neurology at the University of Sydney, Senior Principal Research Fellow - Neuroscience Research Australia, Professor of Medicine, and the University of New South Wales and, Consultant Neurologist at the Prince of Wales Hospital.

Regional Advisor's update

I commenced my appointment, as Regional Advisor, in October and it's certainly been a busy two months! Due to an unavoidable gap between Regional Advisor appointments I realise there may be many of our MND clients who have not been contacted for a while – and for much longer than we would have liked. Therefore, my first priority has been to get in touch and 'check in' with as many clients as possible, and in the vast majority of cases, I have been able to connect in person. At the time of writing this, I had reached just under 50 per cent of our total clients. It has been wonderful to meet so many people who have made me feel really welcome in my new role. In 2015 I will be continuing to contact people, so if we haven't spoken already, I look forward to doing so soon. In the meantime, if you would like to speak sooner I welcome you to get in touch.

In addition to talking to people in the MND community, it was a pleasure to be invited to attend the Gold Coast Carers Group and the Gold Coast Support Group. On both occasions I met a number of members and was able to develop a greater understanding of the issues that are important to these groups. My role, and the work I undertake, is very much shaped by the needs of the MND community and I always welcome new thoughts and ideas– so please don't be shy to share them!

In October 2014 we celebrated Carers Week and you can imagine our surprise when we were contacted by Carers Queensland to inform us that we had been nominated by a client and their family to receive an award! Denise Plunkett-Mansell and I had the pleasure of attending a luncheon and an award ceremony where (on behalf of MND Queensland) we accepted a certificate of appreciation, which recognised our provision of service and support in the community. Ian Kaye, MP for Greenslopes, was in attendance and he expressed his desire to continue advocating in parliament for greater recognition of the needs of those living with MND, which was really encouraging to hear. On behalf of the MNDAQ team, I would like to extend a warm thank you to the family that nominated us for this award.

I anticipate that 2015 is likely to be a very busy year and there are so many more things I am hoping to achieve. Establishing stronger links with all of our MND clients and their families in order for us to provide greater support is of the utmost importance to me. Additionally, I also wish to explore options for more regular support group meetings, and would like to work towards establishing new groups in areas where the opportunity to meet others living with and caring for people with MND doesn't currently exist. There are some other irons in the fire, but as these are very early in the planning stage, I shall have to keep you all in suspense until my next update!

- Dr Amanda Pavey

Fundraiser held in memory of Colin

After losing her father, Colin King, to MND in January 2014, Debbie Bertwistle set out to raise money for MND Queensland. The first fundraising event, an afternoon tea held at Aveo Retirement Village, was held in July, the day before what would have been Colin's 80th birthday and raised just over \$2200. At that event, Debbie shared a poem (see page 11) that she'd written for her father. In November, a charity night was held at the Pine Rivers Rugby League Football Club. The event included live bands, singers, a comedian and, of course, an Ice Bucket Challenge plus a silent auction, raffle and lucky door prizes - donated by local businesses. The event raised \$5,450.00. Debbie said she hoped the money would help make to make a difference in contributing to MND-related research.



Ice Bucket Challenges

The cold hard facts:

Where it all started

The Ice Bucket Challenge for ALS/MND was a social media campaign initiated in the United States. ALS (amyotrophic lateral sclerosis) is known as MND (motor neurone disease) in Australia. Following the first challenge being posted online, the Ice Bucket Challenge quickly went viral including across Australia's MND, sporting and entertainment communities.



Who stepped up to the challenge

CEOs and staff from MND Australia and the state associations, MND researchers and members of the MND community also took up the icy challenge. Here in Queensland, MND Queensland CEO Cheryl Miller kicked things off and members of our Board quickly followed suit. From the MND community we had ice bucket challenges taking place at football events, conferences, backyard pools, public gatherings and even at a wedding!



How much was raised

To date more than \$3,000,000 was raised for MND research and to support people living with MND in Australia. We thank everyone who took part in this incredible awareness and fundraising campaign helping to spread the word about MND.

How the money will be used

Enhanced care and support services, funding for the national MND registry and new MND research grants are some of the initiatives to be funded by the recent MND Ice Bucket Challenges.



60,000 +
Ice Bucket
Challenge Donors



More than
\$ 3 million
poured into MND care,
support and research

Vale

Linda Barlow
Harry Chalk
Gillian Geary
Ann Grgis
Roy Head
Sandra Hobson
Raad Hummadi
Wendy James
Eric Kelly
Rose Kumar
Francois Langlasse
Joan Rodgers
Marion Rutter
Wendy Schimmer
Lorice Seymour
Graeme Ward
Ros Ward
Colin Wright

80 Tomorrow

It hasn't been that long you know
And yet it feels like years,
Since we had to say goodbye
And there were many tears.

I think of you most every day
And wished you'd had more time,
But MND was not your friend
It was a fast decline.

Tomorrow is your birthday
And this I make quite clear,
We'll raise a glass and make a toast
While we drink your homemade beer.

Remember Dad I love you
And this will never cease,
All I hope and pray for is
That you are now at peace.

- Debbie Bertwistle



Key events in 2015



Walk to D-Feet MND

In 2015 we will once again be undertaking our signature fundraising event – the Walk to D-Feet MND and it's set to be bigger than ever, with three events happening across Queensland.

- **Toowoomba:** Sunday 8th March - 10am at Queens Park
- **Brisbane:** Sunday 3rd May - 10am in the Roma Street Parklands
- **Hervey Bay:** Sunday 17th May - 10am at the Hervey Boat Club, Urangan

All walks are approximately a four to five kilometre distance and are open to walkers of all fitness and mobility levels. The events wrap up at midday so there is ample opportunity for everyone to join fellow MND supporters and relax afterwards, enjoy a picnic or BBQ lunch in the parkland setting, plus the entertainment and activities that will be on offer.

MNDAQ & Gasoline Alley HOG Charity Ride

For the second time we will be involved in the Gasoline Alley HOG Charity Ride, which is set to take place on Sunday 19 July 2015. The inaugural event in July 2014 was supported by more than 70 riders and 42 pillions and generated \$11,500 in funds for MND Queensland. AKKA Constructions has set a challenge for next year's event – they will sponsor the existing pillions (42) if the event can attract at least five new pillions for the 2015 ride. So get revved, gather your friends and get involved!



Brisbane Film Fundraiser - The Theory of Everything

The GIFT Club, Fidelis and CK Family Lawyers will be hosting a film fundraiser event, screening The Theory of Everything in January with all proceeds from the event going to MND Queensland.

The Theory of Everything is a British romantic biographical film inspired by the memoir Travelling to Infinity: My Life with Stephen by Jane Wilde Hawking, which deals with her relationship with her ex-husband theoretical physicist Stephen Hawking, his diagnosis of amyotrophic lateral sclerosis (ALS), and his success in physics.

- **When:** Thursday 29 January 2015 – 6.30pm
- **Where:** Palace Barracks Cinemas, Paddington
- **Cost:** \$25 per person, which includes a welcome drink, gift bag and nibbles

To purchase tickets, please call Telisa Sekona on 07 3372 9004.

We will keep you updated on all upcoming event details but in the meantime, for more information you can contact our office on 07 3372 9004 or email info@mndaq.org.au.

Around the traps...highlights from 2014

MND National Conference



Gasoline Alley HOG Charity Ride



Beaudesert Bowls



Dickensons Accountants Walk to D-Feet MND



Hervey Bay Sausage Sizzle



Toowoomba Remembrance Day



Support Group Information

Brisbane West & South

Meet the 1st Saturday of each month at 10am
Contact Denise Plunkett-Mansell – 07 3372 9004

North Brisbane & Caboolture

Meet the 4th Saturday of each month at 9.30am
Pine Rivers Community Health Centre
568 Gympie Road, Strathpine
Contact Graeme Holyer – 07 3888 1783

Sunshine Coast

Contact Rod Downes – 0417 043 095

Gold Coast

Meet the 2nd Saturday of each month from 2pm
The Italo Australian Club
18 Fairway Dr, Clear Island Waters
Contact Lorraine Lovatt – 0408 661 212 or
Denise Darken – 07 5527 3623

Cairns

Contact Anne Kavanagh – 07 4046 8581
anne.kavanagh@health.qld.gov.au

Townsville

Contact Robin Ray – 07 4781 4474
robin.ray@jcu.edu.au

Rockhampton

Contact Anne Thompson – 0407 116 367 or
Gillian Truelson – 07 4934 0493

Maryborough

Contact Evelyn Jacobs – 07 4122 2575

Gympie/Tin Can Bay

Contact Pam Leslie – 07 5486 4022
pleslie@bigpond.net.au

Darling Downs

Meet the 2nd Saturday of each month at 1pm
The Jacaranda Room
Grand Central Shopping Centre
(next to the cinemas)
Contact Telisa Sekona – 07 3372 9004

Motor Neurone Disease Association of Queensland

Established in 1983 and founded by Charles Graham (1925 – 1983)