



In this edition

Community success for Run MND... New MND March of Faces Banner... Thanks to our MND Week volunteers and supporters... Day of Hope and Remembrance... Tumut embraces MND Week 2018... ALSUntangled review of antiretrovirals... Get involved, Make Aged Care Fair... and more

A Message from the CEO

As I write this it is Volunteers Week and, in that vein, I'd like to thank our fantastic volunteers who took part in MND Week at the beginning of May - on Cornflower Blue Day at stations and shopping centres around NSW and the ACT and those who held special events. Read about these and other MND Week events in this *e-news*, including Run MND (pictured above).

I'd also like to take the opportunity to thank all of our volunteers who help keep MND NSW thriving.

MND Week also marks the beginning of our Make Aged Care Fair campaign. Details can be found on page 6. The only way this campaign will achieve its goal of a fairer system is with your involvement. Sign up now.

You may have noticed our Winter Appeal in your email inbox or letter box. Your ongoing generous support allows us to provide essential equipment, support and education to people affected by MND. Please take the time to make a donation and show your support.

Graham Opie



MND Week 2018

Thank you to our volunteers - over 175 of you - who generously gave their time to raise money for MND NSW on Cornflower Blue Day, Friday 11 May and throughout MND Week.



To date you have collected over \$40,000. Thank you for being there for us, we hope you met some wonderful people and formed some great friendships as you volunteered. Many of our volunteers met members of the community who have been touched by MND who came forward to talk and share their story. Thank you for raising awareness, connecting people and starting discussions.

Railway Stations

There were close to 100 volunteers at 14 railway stations on the Sydney network and at Wollongong and Gosford stations. They raised over \$17,000, selling puppies and pens and collecting donations. Thank you for the photos - and for the early morning start. A special shout out to the team of eight at Wynyard who raised over \$5,200.

Shopping Centres

To the 70+ volunteers who manned stalls at shopping centres across the state - thank you - you collected over \$18,000. Shopping centre locations ranged from Wagga Wagga in the south, to Newcastle in the north with Canberra, Queanbeyan and many Sydney and Central Coast locations in between.

Also

Thank you to:

- the generous supporters at the University of Wollongong BioNet for selling our merchandise and holding a bake sale
- Coastline Credit Unions - West Kempsey, Central Kempsey, South West Rocks, Taree, Port Macquarie, Crescent Head, and
- our fabulous volunteers in Nyngan, Young, Grenfell and Wallsend.

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To those in Tumut - your contribution and hard work this year - street stall, raffle and Ice Bucket Challenge - has been a massive success. See page 14 to read about the fun and frolic in Tumut during MND Week 2018.

We could not have organised and run this event without our hard-working volunteers who contribute their time and effort in preparation and set up, at the event and after. Thank you. Let us know if we can count on you next year also!

Ask the Experts

Monday 5 November

West Ryde

Do you want to hear from the experts about the latest emerging MND research and have your questions answered by experts in MND? Then save the date for the *Ask the Experts Forum* at West Ryde! Find out more and reserve your place [here](#).



Living Well with MND Information Day

15 August at Woden, ACT

25 September at West Ryde

Living Well with MND is an informative day for people living with motor neurone disease, their families and friends.

You will be provided with a range of strategies to live well with MND and to maintain independence. You will also have the opportunity to have your questions answered by health professionals with expertise in MND, and to meet others who understand what it is like to live with MND.



There is no cost to attend the program but you need to reserve your place. More information here <http://www.mndnsw.asn.au/all-events/living-with-mnd.html>.

MND NSW Member Survey

Do you still need to return your MND NSW Member Survey? We do value your feedback. It will only take a few minutes to complete, but we need to receive your response by Friday 8 June, so don't delay!

Run MND

On Sunday 6 May, to coincide with the kick off of MND Week, 387 people (primarily residents of the Sutherland Shire, but coming as far afield as the Central Coast, Gundaroo and Tenterfield) ran or walked 5km from Sutherland or 10km from Miranda to Cronulla to raise funds and awareness for motor neurone disease. Several families that have battled or who are battling MND were also in attendance, all local to the Sutherland Shire.



Over \$40,000 was raised for MND NSW support services and MND research into the causes, treatments and cure for MND. This is the third annual Run MND which has raised over \$72,000 in total. The organiser, Sophy Townsend, would like to thank everyone who participated in the event and everyone who generously donated.

Quakers Hill Veterinary Hospital MND Day

Thank you to the wonderful team at Quakers Hill Veterinary Hospital. This is the third year the team have held a great fundraiser for MND NSW. The day included a barbecue, raffle and the sale of MND NSW merchandise, raising \$4,000.



Benefit Day at Kirkham

In May Alexandra Vainauskas generously hosted a Benefit Day for MND NSW in her home. It was a fun day of food and friends with 25 people attending. A total of \$849 was raised from donations and MND NSW merchandise sales.



Join us at the Canberra Walk to d'Feet MND

We recently received a lovely message from one of our members who attended the Walk to d'Feet in Canberra last year. *"I was so inspired by the love and support friends and family gave me at the walk for MND last year. It was a very emotional day looking around at the many supporters all dressed in blue and the MND NSW staff who give their undivided time to help raise awareness for this beastly disease. Cheers, Margie"*. If you haven't yet experienced a Walk to d'Feet MND why not join us in Canberra on Sunday 24 June?



ALSUntangled review of antiretrovirals

ALSUntangled reviews alternative and off-label treatments for people with ALS (PALS). Recently, ALS Untangled have reviewed the use of a class of medications called antiretrovirals (ARVs) for treating ALS/MND (in response to 1400 requests).



Retroviruses are a family of RNA viruses defined by their ability to integrate themselves into the host cell DNA. The review found that based on the lack of evidence for use of ARVs in PALS who test negative for human immunodeficiency virus (HIV) and human t-cell leukaemia virus (HTLV) they cannot recommend ARVs as a treatment for ALS. They do note that there are two ongoing trials of ARVs in PALS and they look forward to the results.

You can read the full paper [here](#) and find out more about ALSUntangled at <http://www.alsuntangled.com/>.

For Sale

White Holden Combo 1998 5 speed Manual. Converted and certified for full-size wheel chair access. 12 mths reg 83,000 genuine kms. Air con, reverse parking camera. \$9,500 ONO. Phone Tina 0478 538 520.

Have you joined the campaign to Make Aged Care Fair?

In MND Week we announced the launch of Make Aged Care Fair – a new campaign that calls on the Government to make sure people diagnosed with motor neurone disease when aged 65 or over have access to the right care, in the right place at the right time. We need your help to make sure our decision makers listen.

We know Aged Care services are failing people with MND and many are being pushed into financial hardship or residential aged care earlier than they wish. Many people with MND are waiting for a Community Aged Care Package or have been assigned a lower level package that does not meet their needs and many are also facing stressful and unnecessary reassessments.

MND Australia and the MND Associations believe this is wrong and unfair and that's why we are calling on our decision makers to Make Aged Care Fair, but we need your help to make sure they listen.

Join the campaign and help make sure that everyone with MND has access to the right care, in the right place, at the right time, irrespective of age.

Check out our brand new [MND Action](#) website to find out more information and join the campaign to make sure the voices of people with MND are heard. Act now and join the campaign to Make Aged Care Fair for people with MND diagnosed when aged 65 and over.



Julie and Bob Flack are experiencing multiple problems with Aged Care

Join the campaign

Reflections on Day of Hope and Remembrance 5 May 2018

This very special day held on the eve of MND Week was attended by 112 people whose lives have been affected by MND. Our guest speaker, Janet Nash, Executive Officer Research, MND Australia, spoke about the development of MND research in Australia. The MND Association of NSW was formed in 1981 and in 1986 the Association, together with the other state and territory MND Associations, became a founding member of the MND Research Institute of Australia (MNDRIA), which amalgamated with MND Australia in 2010. The first MNDRIA research grant was awarded in 1988 for \$19,038. Over the last 30 years more than \$25 million has been invested by MND Associations, MNDRIA and MND Australia in Australian health and medical research into MND. Janet concluded her talk by saying that there is much hope for the future of MND in the research community.



Janet Nash

At our Day of Hope and Remembrance we acknowledge people whose lives have been touched by MND including people living with MND, their family, friends, those who have lost their lives to MND, professionals working with MND, researchers and supporters. A candle lighting ceremony is held with people sharing their dedications. These dedications are very heartfelt and a few of these are shared below.

MND NSW board and staff: Ralph Warren

"It is my privilege and honour to be here today representing the board, our dedicated staff and the numerous wonderful volunteers at this function which marks the beginning of MND week. This candle is lit to signify the continuing fight against this horrid disease and as a symbol of remembrance for those who have bravely succumbed to its ravages."



Ralph Warren

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All staff, board and volunteers, do what we do in organising and delivering services and assistance to people living with MND, as well as raising funds for research, because of what we have seen in the past, and what we see here and now before us today.

You brave people living with MND and your wonderful carers inspire all of us to do what we can to ease your everyday burden and to pursue knowledge of the causes of this terrible disease. A cause and cure will be found, but until that time we will remain by your side to give whatever assistance and support we are able to provide."

Family and friends of people living with MND: Ros Emslie

"Today, we light this candle to acknowledge the enormously important role that family and friends play in providing love, care and support to people who are living with MND.

Since my very close friend Danielle was diagnosed with MND two and a half years ago I have watched in awe as she has adapted to her changing abilities. The simple things that we always take for granted like walking, eating and talking have become more challenging but her resolve and need for independence and a 'normal' life has never wavered.

Supporting Danielle along the way are her beautiful family, husband Russell and sons Ryan and Cam. I have been amazed at the quiet ways that their support has come. They are with you every step of the way, every day for life's big and little things.

I know that Danielle and her family have been overwhelmed by the enormous amount of community support that they have received in their fundraising efforts for MND which is testament to the esteem in which they are held within our community. Everyone is with you.



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If you are living with MND be assured that you are surrounded by people who really care and desperately want to help you and your family. They may not know how to help, so give them guidance so that you get all the support you would like and need. Sometimes it might be something as simple as dropping in, having a chat or it might be more. We, your family and friends, are all on this journey together.

Today, this candle is being lit for everyone who is facing the myriad of challenges that MND presents."

Supporters and volunteers: Zakhia Aoun

"This candle is being lit to honour the supporters and volunteers who show strength, generosity and advocacy in the name of MND.

These amazing people consist of those who have been touched by MND personally and continue to have a voice for their loved ones, and others who chose this to be the cause to speak out and support. Whilst it is their fight to fight, we

collectively can be present, to hold their hands, wipe their tears, speak on behalf of them and raise awareness of MND so that the lives of those affected are always remembered and those lives who may be affected in the future are either minimally so and at some stage the illness is eliminated.

We dedicate this candle to the volunteers and supporters who bring a voice and hope for those living with MND and the means for those working tirelessly to find a cure."

We would like to acknowledge and thank all those involved in this special day and especially Soka Gakkai International Australia who each year allow us to use their beautiful venue free of charge.

Gina Svolos

Manager, Support Service

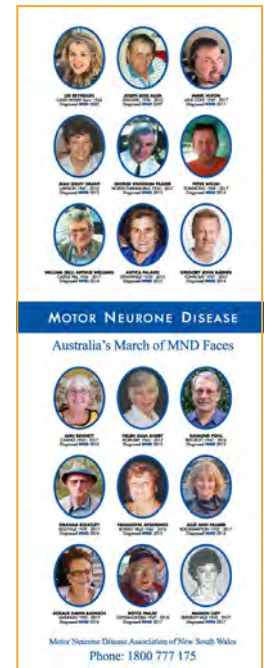


Zakhia Aoun

MND March of Faces Banner 20 now online

The MND NSW March of Faces banners are displayed at various MND awareness raising and remembrance events throughout the year. Our MND March of Faces Banner 20 was displayed for the first time during MND Week 2018.

March of Faces Banner 20 features Joseph Ross Allen, Panagiota Avgerinos, Gregory John Barnes, Rosalie Dawn Baensch, Ann Bennett, Graham Bulkeley, Royce Finlay, George Kinnison Fraser, Jean Lesley Grant, Marion Luff, Mark Nixon, Antica Palaric, Julie Ann Palmer, Raimund Pohl, Lee Reynolds, Helen Julia Short, Peter Welsh and William (Bill) Arthur Williams. You can view March of Faces Banner 20 [here](#).



Upcoming community fundraising events

2 Jun **Luskintyre Family Fun Day**
Luskintyre Airfield



10 Jun **Plunkys Ride for MND**
Ourimbah Rest Stop



23 Jun **Glenn Sargood MND Fundraiser**
Yerrinbool Oval



27-30 Jun **Australian Bee Congress**
RACV Royal Pines Resort, Benowa, Gold Coast

7 Oct **Bunnings Sausage Sizzle**
Eastgardens

13 Oct **Gundaroo Music Festival 2018**
Gundaroo Park



Do you have an idea for an event to raise funds for MND care, support and research? [Find out more here.](#)

It's a wrap - Port Macquarie and Southport

We had a great turnout of 35 people attending *Living Well with MND* at Port Macquarie on Friday 25 May, with some travelling from Grafton, Taree and the Central Coast to be there.

We are grateful to the allied health professionals from Port Macquarie Base Hospital, Port Macquarie Community Health and Mid North Coast Local Health District who presented. Kylie Ballantyne, physiotherapist, and Sally Tonkin, occupational therapist were a dynamic duo demonstrating techniques and equipment that can help with showering, mealtimes, mobility, comfort. They also covered exercise and MND, how to manage fatigue because "fatigue is fatiguing", how carers can protect their backs, preventing falls and more.

Elizabeth Levido, palliative care nurse, debunked some myths people often have about palliative care. Elizabeth emphasised that the primary treatment goal is to optimise quality of life. Joanne Pretty, dietitian, advised on the importance of maintaining weight and making every mouthful count. It was good to hear her say to eat plenty of butter, full cream milk, cream and custard! Kate Meredith, speech pathologist, retitled her presentation from 'communication, saliva management and swallowing' to 'let's chew the fat' and gave an informative presentation with tips and tricks on how to do this.

We maximised our time in Port Macquarie and conducted an *MND Aware* training on Thursday 24 May specifically for allied health and community care professionals with 23 attending, including three National Disability Insurance Agency planners. All attending said they valued the case studies, discussions on symptom management and networking with others to promote multidisciplinary care in MND.

On Wednesday 23 May 40 people attended *Living Well with MND* at Southport, Queensland, with terrific guest speakers and great feedback from attendees. We focused on occupational therapy, physiotherapy, respiratory issues and access to local services. Thank you to the MND and Me Foundation and Carers Qld for their financial support so this event could be offered free of charge to participants.

Upcoming Support Service events

Click to find out more.

19
Jun

Information Evening for people recently diagnosed with MND
Gladesville

14
Aug

Information Evening for people recently diagnosed with MND
Gladesville

15
Aug

Living Well with MND
Woden, ACT

17
Sep

Past carers lunch
Gladesville

25
Sep

Living Well with MND
West Ryde

16
Oct

Information Evening for people recently diagnosed with MND
Gladesville

17
Oct

Celebrating National Carers week morning tea
Gladesville

5
Nov

Ask the Experts Forum
West Ryde

1
Dec

Members' Christmas Party
West Ryde

4
Dec

Information Evening for people recently diagnosed with MND
Gladesville

MND support groups and coffee mornings

MND support groups and coffee mornings are held in city, regional and rural areas of NSW, in the ACT and on the Gold Coast, Queensland. Find out more [here](#) or speak with your MND Advisor.



Together, let's take steps to d'Feet MND

Join us at a 2018 Walk to d'Feet MND. Teams made up of family, friends, colleagues and individuals, regardless of age or fitness levels, walk to raise funds and awareness for research and support for people living with motor neurone disease.

Why not join in the fun at a 2018 Walk to d'Feet MND?

Sun 24
Jun

Walk to d'Feet MND Canberra

Peace Park, Parkes, ACT

Register now

Supported by



Sun 15
Jul

Walk to d'Feet MND Penrith

International Regatta Centre, Castlereagh

Register now

Supported by



Sun 26
Aug

Walk to d'Feet MND Batemans Bay

Corrigans Beach Reserve, Batehaven

Register now

Supported by



Sun 16
Sep

Walk to d'Feet MND Port Macquarie

Westport Park, Port Macquarie

Register now

Supported by



Sat 13
Oct

Walk to d'Feet MND Wagga Wagga

Apex Park, Wagga Wagga

Register now

Supported by



Sun 4
Nov

Walk to d'Feet MND Sydney

Blaxland Riverside Park, Olympic Park

Register now

Supported by



MND Week 2018 in Tumut

Annemarie Young, Janice Alchin and Rebecca Prior

We had a very successful fundraising week in Tumut during MND week 2018. On Friday 11 May, for Cornflower Blue Day, we had our annual MND Street Stall selling MND merchandise, raffle tickets and dozens and dozens of delicious caramel tarts and patty cakes baked by Mary Ballard whose husband, Chris, died from MND in 2015.

In spite of it being a freezing cold, wet day (it was snowing not far away!), we still did very well. Our wonderful volunteers were all rugged up! It seems they were already preparing for the Ice Bucket Challenge!

The next day was our much anticipated Ice Bucket Challenge! The thermometer was slightly higher, though it was overcast all day. That did not deter the supportive crowd or our 16 brave participants ('victims'!) who were readying to be 'dunked' with ice and freezing water.

As the theme was 'pool party' the participants had put much thought into their costumes. We had two beautiful mermaids, three exotic hula girls, a fierce dragon, a very brave scuba diver, a keen life guard and a tuxedo clad gentleman, dressed to go to the 'ball'! After all, it was a 'pool party' wasn't it? He did manage to go to the 'ball'! But the 'ball' was in the pool. Some brave young sporty men even bared their upper half to be 'dunked', much to the delight of the crowd!

John Deacon was our illustrious MC and auctioneer and kept the momentum going.



(L-R) Annemarie Young, Caroline Bujaroski and Janice Alchin rugged up at the annual Tumut MND Week Street Stall

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*Clayton Ballard (above) and
Caroline Bujaroski (below)*



*Dave Shedden (above) 'dunked'
by his former neighbour,
for getting him the wrong
beer once*



*Tim Oliver, Tumut Rotary Club
President (seated left with the
party ball) with Albert
Manning, Tumut Lions Club
President, in the tuxedo
getting 'dunked'*

'Dunking' was by the highest bidder. Among them, we had a mother 'dunking' her adult daughter (for being a terrible toddler), two daughters 'dunking' their fathers (showing no mercy – 'what comes around goes around'), a physiotherapist 'dunking' her personal trainer (for pushing her too hard at the gym), a husband 'dunking' his wife (for all the cold shoulders over 35 years), workmates, neighbours, and a young Rotary Exchange Student from Germany, who 'dunked' two victims and was then 'dunked' himself.

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The Rural Fire Service kept the buckets coming. It was all in a day's work for them until one of them took the bucket himself – with his daughter savouring the moment!

The Challenge was particularly poignant for six of the participants who had witnessed firsthand the cruel effects of motor neurone disease.

They were doing it for their loved ones who had died from MND - Scott Anderson for his mum, Colleen; Caroline Bujaroski for her dad, Russell Breward; Kelvin Matchowitz for his father in-law, Chris Ballard; Clayton Ballard, for his pop, Chris Ballard; Belinda O'Brien, for her uncle, John Sutton; and Dave Shedden for his uncle, Tom French.

Following the Ice Bucket Challenge the raffles were drawn, and we had six very happy winners.

But there was still more fundraising to come!

The next day we had a bucket collection at the Tumut Blues Group 9 versus Albury Thunder rugby league match in Tumut. Two of the Ice Bucket Challenge participants were on the field playing for the Tumut Blues. The ice must have spurred them on, as Tumut won 28-18.



Kelvin Matchowitz (above) getting dunked by his daughter and Marie Peachey (below) getting 'dunked' by her husband for all the cold shoulders over 35 years!



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Over the last few months our 16 Ice Bucket Challenge participants were very busy doing their own fundraising towards the Challenge. Nothing was too much trouble for them. We appreciate all they have done to raise awareness and understanding of MND and we thank them most sincerely for their tremendous fundraising efforts and for wanting to make a difference. They are true champs!

Although the Ice Bucket Challenge was a bit of fun, in no way does it detract from the seriousness of MND. Through all of our activities we were able to raise public awareness about MND and also much needed funds to support those living with MND and their families.

With the street stall, raffles, footy bucket collection and all the donations and fundraising for the Challenge, Tumut has raised over \$23,500 to date, with more still coming in! Kudos to the community for their support of the participants and all of the MND Week activities.



Allegro Sprute the Rotary Exchange Student from Germany (above) bravely doing his bit and Emma Alchin (below) getting 'dunked' by her mother for being a terrible toddler.



The enthusiastic crowd



Motor Neurone Disease Association of New South Wales

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

Ph 02 8877 0999 Freecall 1800 777 175 Fax 02 9816 2077

admin@mndnsw.asn.au <http://www.mndnsw.asn.au>

 <http://fb.me/mndnsw> ABN 12 387 503 221

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Jasminka Gojkovic,

Lauren Lovegrove,

Samantha Potter, Marnie

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Stamford

Admin Assistant NDIS

Brenda Smith

...and many valued
volunteers