

Run MND 2019



In this edition

MND Week... Cornflower Blue Day... Day of Hope and Remembrance... Potential game changer for rare and genetic diseases... Results of Phase 2 FORTITUDE-ALS clinical trial... Run MND and Walk to d'Feet Illawarra and Hunter supporters show they care... Ask the Experts... and more

A Message from the CEO

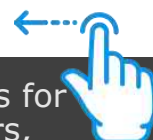
I'd like to thank everyone who took part in MND Week. With our Walks to d'Feet MND in Illawarra and the Hunter bookending the week, and Run MND, it was a fantastic example of Together We Can!

Throughout MND Week volunteers reached out to many people across all walks who may have not known much about MND. Our Day of Hope and Remembrance, our Walks in the Illawarra and the Hunter combined with the two Run MND events allowed over 2000 people, who know of the devastating effect of MND to get together and raise funds for support, equipment and research.

The visibility and knowledge of MND in the general community has increased dramatically through the efforts of the many volunteers who give so much of their time. Thank you.

Together we can break down the barriers.

Graham Opie



Together we can

Once more, at the conclusion of MND Week (5-11 May), we have lots of good news to share and thanks to express! Our biggest thanks go to our 150 volunteers who initiated, organised, led and manned merchandise stalls and fundraisers for us throughout MND Week and on Cornflower Blue Day.

Together, they increased the visibility of MND at 29 locations across NSW and ACT and raised almost \$30,000 that will enable us to provide support, education, information and equipment to our members, their families and friends.

Wynyard Station was our top fundraising location. Our Wynyard team raised \$3700 in the three to four hours that they were there. Our Town Hall Station team raised \$2600 and teams at Bondi Junction, Parramatta, and Circular Quay each raised more than \$1000. If you didn't join a fundraising team this year, you may want to consider it next year. There's a lot of fun to be had on Cornflower Blue Day!

A big thank you also to Loretto Kirribilli. Loretto students raised \$1600 through various events held on Cornflower Blue Day.

Thank you to Lyn Pennock and her team at Chester Hill who raised \$3600 by selling hand made items. These fantastic ladies have now raised over \$80,000 for MND NSW over the years.



To all our teams at shopping centres, thank you for being our face in the community. The awareness you raise is invaluable, not to mention the funds.

To our crews in the country – wow! Country people have big hearts! The folks in Tumut raised \$3000. Those in Wagga Wagga close to \$2000. Thank you!

A shout out also to Coastline Credit Union branches who showed their support again this year.

All of you who volunteered on Cornflower Blue Day and throughout MND Week made an invaluable contribution. Without volunteers, we could not continue to do all we do for our members. THANK YOU ALL!

Together We Can.

Sarah Bouch | Volunteer Coordinator

A special thank you to Sarah and Victoria

Loreto Kirribilli students Sarah Scalercio (Year 8) and her sister Victoria (Year 11) held a fundraising day on 8 May to raise awareness about MND as well as money for research. Sarah said of the day, "My sister Victoria and I organised the fundraiser as it is a charity close to our hearts. Last year our father died from MND and we are determined to make a difference and support this worthy cause."



It was an extraordinary effort that raised \$1300! A huge thank you to all the Year 8 students who baked, helped sell and collected money, and to Mrs Cooke for helping to organise the event. Most importantly, thank you to the Loreto Kirribilli girls who supported the cause and made the day the success it was.

Dale's Day 2019

A big thank you to Joanne Moroney who organised her third Dale's Day event, raising \$3150 in support of MND NSW. Around 80 family and friends gathered for a barbecue and picnic, along with a fantastic game of cricket!

Our thanks to Joanne and her family and friends for their continued support.



Support Service Update

Our annual Day of Hope and Remembrance was held on 11 May and was again a very moving and important day honouring all those who have been affected by MND. I am deeply grateful to those who shared their journeys through their dedications and those who lovingly shared the occasion not only with their presence but by their unspoken and unwavering support for our entire MND Community. I would also like to say how proud I was of the MND NSW team for working to make the day so special for us all. As this was my very first attendance at Day of Hope and Remembrance, I was moved not only by the poignancy of the day but also by the hope that was shared for a future without MND. It was truly my honour to be part of the day. You can read more about the event and the special dedication from Sunita Singh, on behalf of people living with MND, on page 14.

Change and renewal is an inevitable consequence of life and so it is, with our Support Service team. We will shortly say a fond farewell to Lauren Maxwell, MND Advisor for Newcastle, mid North Coast and New England regions. Lauren is leaving us to take up new opportunities and does so with our warmest wishes for success.

At the same time the Support Service team is also about to grow again, with the addition of a new member of the Coordination of Support team. It is a testament to the work that this team does that the demand for their services continues to increase.

Recruitment for both roles is currently underway and we hope to be introducing you to our newest team members in the next edition. If you have any questions or concerns during these periods of transition, please do not hesitate to contact me ph. 8877 0999 or karenm@mndnsw.asn.au.

I am currently looking for up to 15 Members or Carers who would like to take part in a pilot of an MND NSW Online Chat and Connect Session on 27 June at 10am. The session will run for approximately an hour. It is not intended as a formal training session, but rather a space where you can come to connect others living with MND and us. To participate in the session you will need a device which has a microphone/camera and internet access such as desktop computer, laptop, tablet or phone.

We are therefore seeking a few brave souls who will work with us to test the program before scheduling in regular online Chat and Connect sessions. If you are interested, especially those of you who live outside the Sydney metropolitan area, then please email reg@mndnsw.asn.au with Online Chat and Connect in the subject line.

Karen Martin | Manager, Support Service

Run MND

On Sunday 26 May Run MND Sutherland Shire saw 425 participants smash out either a 5k or 10k walk or run at Don Lucas Reserve and Wanda Beach in Cronulla. This year's new Sutherland Shire route was tough but everyone finished with a smile on their face having completed the course.



On the same day 230 inaugural Run MND Central Coast participants completed their 5k or 10k walk or run at Long Jetty Foreshore.

With Run MND Sutherland Shire raising over \$63,000 and Run MND Central Coast raising \$17,000, a phenomenal \$80,000 was raised for MND support services and MND research by the participants and their supporters. A big thank you to the event sponsors and to our community fundraisers Sophy Townsend and Kim Lindsay.

City2Surf

Join Team MND and become an MND Superstar. MND NSW and MND Australia will have a combined team for this year's City2Surf. You can apply now to become a Superstar. Minimum fundraising of \$1,000 is required.



Superstars will start at the front of the pack and receive free entry to the City2Surf. Together we can break down the barriers for people living with MND but we need your help to provide MND Advisors, education for people with MND, a dedicated info line and equipment as needed. Commit to raising \$1,000 today and join Team MND for the 2019 City2Surf.

Thank you to our supporters

Walk to d'Feet MND Illawarra

5 May 2019

Bulli Surf Club, Bulli NSW

The Illawarra Walk to d'Feet MND is over for another year and what an event it was. Despite the challenge of rain, it was one of our most successful Walks in the Illawarra yet, raising more than \$23,000!

A big thank you to our wonderful sponsors Bulli Surf Club, Woonona Lions Club, Duncan Stockcrates, i.98, Win TV, Grand Ridge Brewery, Xpresso Mobile Cafe Wollongong, Responder1, and Waliscags and to our wonderful volunteers. Thank you, also, to the amazing team at Illawarra Health and Medical Research Institute. It was great to see you there. *Supported by*



Thank you to our supporters

Walk to d'Feet MND Hunter

26 May 2019

Speers Point Park, Speers Point NSW

We returned to Speers Point Park this year for Hunter Walk to d'Feet MND and we had an incredible response with 858 participants raising \$71,824. It was a fantastic day - so many people joined in companionship with purpose - raising vital funds for people living with MND and funds for research to find the cure.

A big thank you to Grand Ridge Brewery for the top fundraiser and top team cider packs; Kennards Hire for tables and chairs for registration, T-shirt and merchandise stands; and the lovely folks from Sugar Valley Neighbourhood Centre for managing the barbeque and donating the funds raised to the Walk. Thanks Hunter. See you next year.

Supported by



Together We Can 2019 Walk to d'Feet MND

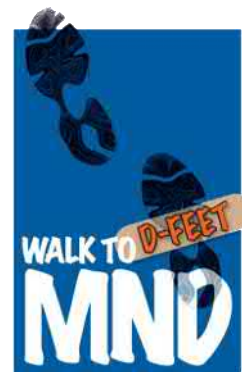
Register today at walktodfeet.org.au and raise funds when you participate.

Show your support for people living with MND.

In 2019 we have made it even easier for you to register for a Walk to d' Feet MND and raise funds when you participate. All of our Walks and the local information for each venue can now be accessed through the one site. Register today at <https://walktodfeet.org.au>.

I look forward to seeing you at a Walk in 2019. Together We Can.

Kym Nielsen | Fundraising Manager



16
Jun

Walk to d'Feet MND Canberra *Supported by*
Peace Park
Parkes ACT



14
Jul

Walk to d'Feet MND Penrith *Supported by*
International Regatta Centre
Castlereagh NSW



8
Sep

Walk to d'Feet MND Taree *Supported by*
Endeavour Place Reserve
Taree



20
Oct

Walk to d'Feet MND Young *Supported by*
Arboretum Park
Young



3
Nov

Walk to d'Feet MND Sydney *Supported by*
Sydney Park
Alexandria



New Carers Gateway

We are always conscious of the needs of the many carers in our community, so it was good to see information starting to finally roll out about the new Carers Gateway.

From September 2019 carers will be able access services such as counselling, support groups or emergency respite services through the gateway. It is expected that the nationwide roll out will be complete by the end of the year.



The website www.carergateway.gov.au and the main contact number, 1800 422 737, are already operational but limited to details of carer services currently available. From July the site will be updated with details of new initiatives which were part of the \$84.3million investment in services for carers announced in the Australian Government's 2019 budget.

From September this year carers looking for support or services will be able to call the 1800 number and speak to Gateway staff about their needs or to request support. Nine types of support will be available including:

- online peer support, counselling and coaching
- face to face support, peer support, counselling and coaching
- carer directed packages
- emergency respite care.

One of the most exciting aspects of the new Gateway is the ability for Carers to access Carer Directed Packages. The first package planned is a 'one off' payment of up to \$1500 for the purchase of items that either support the caring role or assist carers to access employment or education opportunities. The second package is proposed as a payment of up to \$3000 to allow carers to purchase assistance with household tasks such as cleaning, cooking, transport or to access respite services.

The budget announcement noted that there were 'over' 5,000 packages available to service an estimated 2.7 million carers. Unfortunately, there was no detail as to how far over the 5,000 number the packages went, so we would encourage you to bookmark the Gateway website and check regularly for when these become available.

To access one of these packages, carers can self-refer to the Gateway. We understand that these payments are not means tested and are additional to any package that may be in place for the person being cared for. When the packages become available we will provide more information of the exact processes for accessing these. Like you, we will be watching with interest as to how the packages are rolled out and how carers are prioritised for supports.

The suite of new supports will be delivered by Carer Gateway service providers. We expect these to be announced in July 2019 when the transition to the new services commence. For now, you can speak with Carers NSW who continue to support and advocate on behalf of carers.

More information

- Budget Announcement - www.dss.gov.au/sites/default/files/documents/04_2019/pbs-fact-sheet-carer-support-serviceslfexzjs.pdf
- Carers Gateway - www.carergateway.gov.au/
- Carers NSW - www.carersnsw.org.au/

Sign up now for Ask the Experts!

Monday 12 August, West Ryde

Here's your chance to hear from experts in the fields of MND research and neurology, and to ask questions.

Our *Ask the Experts* forum is an opportunity for people living with MND, their family and friends to learn the latest developments in MND.



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

There is no charge to attend *Ask the Experts* but you will need to RSVP by 7 August! So, reserve your place now. Morning tea and lunch will be provided.

To RSVP or for more information contact reg@mndnsw.asn.au or ph. 8877 0999 or Freecall 1800 777 175.

Results of Phase 2 FORTITUDE-ALS clinical trial

Results from the Phase 2 clinical trial of FORTITUDE-ALS have recently been made available. Here is the update from MND Australia:

"The trial failed to meet either of its primary or secondary endpoints, with the trial finding the following: no statistical significance demonstrated for change in slow vital capacity (SVC) from baseline following 12 weeks of dosing; and dose-response analyses for the secondary endpoint failed to demonstrate statistical significance between reldesemtiv and the placebo arms.



However, data did reveal that all patients who received reldesemtiv declined less for both SVC and ALSFRS-R (revised Amyotrophic Lateral Sclerosis Functional Rating Scale), when compared to those taking the placebo. The full press release from the American Academy of Neurology is available at <http://ir.cytokinetics.com/news-releases/news-release-details/cytokinetics-announces-results-fortitude-als-phase-2-clinical>.

A spokesperson from Cytokinetics said: "While FORTITUDE-ALS did not meet the primary endpoint, we are encouraged by the results of the trial as they further validate the potential of skeletal muscle activation in treating patients battling ALS ... This Phase 2 trial of reldesemtiv demonstrated consistency of effect for doses, endpoints, and time points and we believe the results support progression of reldesemtiv in further clinical trials toward potential registration."

Cytokinetics has recently uploaded a webcast at <http://ir.cytokinetics.com/> that discusses the results of the trial in further detail.

A fantastic night of trivia

Congratulations and a very big thank you to Alli Young and everyone who helped organise a Trivia Night recently at the Hunter Belle Cheese Cafe in Muswellbrook.

The event was a great success raising \$5240 in support of this year's Walk to d'Feet MND Hunter. Pictured is the fantastic support crew from the event!



MND Education has been travelling north

Each year, MND NSW organises education days at various locations across NSW and the ACT to bring important information to people with MND, their family and friends, as well as health and community care professionals.

We hold *Living Well with MND* days four to five times a year. In 2019 we have already been to Orange and to Newcastle. We have further *Living Well with MND* days planned in Berry on 24 September and Ryde on 22 October.

If you are living with MND, or you are a family member or friend of someone living with MND, we invite you to attend one of these events. They are informative and light-hearted days when health professionals from the area speak on such subjects as nutrition and MND, breathing and MND, how to live better for longer, equipment and aids that can assist, managing saliva, and more. There is no cost involved. For more information contact the MND Info Line ph. 1800 777 175.



In the last couple of months, our focus has been Newcastle. On 11 April we held *Living Well with MND* at Charlestown Bowling Club. We were delighted that more than 55 people attended the event. Almost 20 people living with MND came along, and almost twice that number of carers, family, and friends.

Our education days also include events for health and community care professionals. On *MND Aware* days, service providers learn about MND, interventions that can help, the emotional impact of MND on the person living with the disease, their family and even on the healthcare professionals who care for them.



On 16 May, Eileen O’Loughlen, MND Advisor Team Leader, and Kristina Dodds, Education and Carer Support Coordinator, spent the day with 19 service providers, including occupational therapists, physiotherapists, coordinators of support, speech

pathologists and nurses. Contact the MND Info Line ph. 1800 777 175 if you would like to be kept informed of future events for health and community care professionals.

Later this year we will be heading back to the Hunter Valley, this time for a two-day *Link and Learn* residential program specifically for family carers. The overnight event will be held at the Hunter Valley Resort from Thursday 7 November to Friday 8 November. There is no charge to attend but places are limited. If you are an MND family carer and are interested in attending contact the MND Info Line ph 1800 777 175 or email reg@mndnsw.asn.au or see more information here www.mndnsw.asn.au/what-we-do/education/89-link-and-learn.html.

Taking Control of Our Genetic Destiny - a leading researcher speaks as both patient and scientist

On 20 May Sydney University hosted a public lecture with Dr Monkol Lek, a scientist exploring a new frontier in genetics at Yale University. Dr Lek's work shows that it's possible to manipulate the human genome, to change the structure of an individual's DNA and to "correct" an individual's cells. His findings have the potential to be game changing for a number of genetic and rare diseases.



Dr Lek's personal story is incredible, too. When he was in his early twenties, he was diagnosed with a rare medical condition – limb girdle muscular dystrophy. He took matters into his own hands, retrained in genetics (pivoting from an engineering degree/career), and is now actively turning the tide of his disease.

This overlap of innovative science and personal experience flavours Dr Lek's lecture. He presents his insights using three case stories, one being his own. You can listen to the podcast at <https://soundcloud.com/sydney-ideas/monkol-lek>, or read the transcript at <https://sydney.edu.au/news-opinion/sydney-ideas/2019/monkol-lek.html>. You can also view an additional lecture given as part of TEDx Sydney 2019 by going to <https://tedxsydney.com/event/tedxsydney-2019>.

Day of Hope and Remembrance

Our Day of Hope and Remembrance 2019 on 11 May marked the conclusion of National MND Awareness Week. One hundred and forty members of the MND community gathered together to remember and honour all those whose lives have been touched by MND, and to hold hope for the future.



Thanks to Alex and Megan Cronin who played exquisitely throughout the day, creating a lovely atmosphere in which to share afternoon tea with friends both old and new.

Professor Ian Blair, Director and Group Leader at the Macquarie University Centre for MND Research, a leading researcher into the genetics of MND, was our speaker on this special occasion. He inspired all by speaking about the advances being made in MND research, both in Australia and worldwide.

Equally inspiring were the touching dedications written from different viewpoints within the MND community. Thanks to all who so kindly agreed to write dedications and to participate in the candle-lighting ceremony. Below is the moving dedication from MND NSW member, Sunita Singh, who represented people living with MND



Dedication on behalf of people living with MND

By Sunita Singh

Good afternoon friends.

Thank you for joining us here today in this journey of hope and remembrance.

We are all together in this fight with the Most Notorious Demon - MND. Yes, that seems like the most suitable analogy for this debilitating disease that takes away our dear and near ones while we watch helplessly. But NOT ANY MORE.

Two years ago I was diagnosed with MND and I am determined not to be defeated and I mean it. Let the monster take its course and I will take mine. During my journey I have met courageous family members who inspired me with their optimism and filled my life with hope, even

though they may have lost their loved ones to MND. Thank you all for letting me learn from your profound experiences. Let me share with you my strategy to defeat MND.

I am not asking anymore WHY ME? I look straight into the eyes of this demon and say WHY NOT ME?

I am fully supported with tools of the trade via MND NSW - and together with them I am continuing to break down the barriers for people living with MND now and those to come.

I am able to do this with the support of health professionals and as a result of the ongoing research which seems to be near a breakthrough. Until the time there is cure, there is care. Believe me, my friends, this is no ordinary care. This is the loving CARE of family and friends that helps us sail through difficult waters. This is the CARE that will make a difference. This is the CARE that will show us the light at the end of the tunnel. This is the CARE that is our most powerful weapon in the fight against MND. This is the CARE that will dictate victory over defeat.

This is the CARE I need most, and you need most.

Thank you, my care givers, from the bottom of my heart for your relentless efforts and support to show me the hope. To show me the true meaning of life in all its vulnerability and proximity to uncertainty. To show me the courage you demonstrate in encouraging me. To help me strengthen my thoughts in the powerful philosophy of hope and belief. We are the chosen ones and we will live up to the challenge. Please keep smiling and DO NOT STOP living. Please rejoice and live your life...you live every day and you die only once - so do not stop living.

Let's feel empowered rather than feeling overwhelmed and bring that transformational change that will change the way we live with MND.

Deep in my heart I do believe we shall overcome MND someday. This is my strong belief that day is not too far.

I will conclude by this quote from Walt Whitman

"Keep your face always toward the sunshine and the shadows will fall behind you "

Thank you

Sunita



Upcoming Support Service Events

Click the event for more information.

12
Aug

Ask the Experts Forum
West Ryde

17
Sep

Past carers lunch
Gladesville

24
Sep

Living Well with MND
Berry

10
Oct

Celebrating National Carers Week morning tea
Pennant Hills

22
Oct

Living Well with MND
West Ryde

7-8
Nov

Link and Learn
Hunter

MND support groups and coffee mornings - 2019 calendar

MND support groups and coffee mornings provide the opportunity for people living with motor neurone disease to meet together regularly to chat and learn from each other. Regular meetings are held in the ACT, Campbelltown, Central Coast, Gold Coast, Illawarra, North West NSW (Tamworth), Northern Beaches and Northern Sydney. Meetings are also held from time-to-time in the Northern Rivers and Wagga Wagga/Albury areas. See the [full 2019 calendar online](#).



Do you have a compliment or complaint about our service?

Your comments and concerns help us to improve our services, and your compliments let us know which aspects of our services you particularly appreciate. You are welcome to provide your feedback to Karen Martin, Manager, Support Service, ph. 02 8877 0999 or 1800 777 175 or karenm@mndnsw.asn.au.

Community Calendar

Click the event for more information.

15
Jun

MND Fundraiser Event
Woy Woy Leagues Club

18
Jun

Riddla MND Golf Fundraiser 2019
NSW Golf Club, La Perouse

22
Jun

Glenn Sargood MND Fundraiser
Yerrinbool Oval, Yerrinbool

29
Jun

Lift4MND
RealFITT

28
Jul

Bunnings Balgowlah Sausage Sizzle
Bunnings, Balgowlah

28
Jul

East Hills Charity Car Show
Kelso Oval, Panania

10
Aug

Saturday Night Italian Cinema
Event Cinemas, Kotara

26
Oct

Gundaroo Music Festival 2019
Gundaroo

New listing on find.mndhub.org.au

The online directory at find.mndhub.org.au provides information about services and resources that may be of interest to people living with MND. Recent new and updated listings include the following:

- TabTimer is an Australian Company supplying devices that help keep medicines and regular personal-care tasks on time by using assistive technology and assisted listening reminders. The range includes electronic pill boxes, automated pill dispensers, medical watches, vibrating watches and clocks, talking watches and talking clocks, memory aids, doorbell signallers and alerting devices and accessories.



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

Together we can break down the barriers for people living with MND

VICE PATRONS Melinda Gainsford Taylor, Kevin Langdon OAM, The Hon. Mr. Justice Peter W. Young OA

AUDITOR Walker Wayland NSW

MND NSW BOARD **President** Lara Kirchner **Vice Presidents** Amy Critchley, Roger Henshaw **Secretary** Anita Richter **Treasurer** Nick Shaw **Board Members** Kirsten Harley, Ann Tout and Ralph Warren

STAFF

Chief Executive Officer

Graham Opie

Fundraising Manager

Kym Nielsen

Community Liaison

Amanda O'Farrell

Fundraising Assistant

Maxine Williams

Volunteer Coordinator

Sarah Bouch

Admin and Finance Manager

Brenda Smith

Receptionist

Arja Aladjadjian

Accountant

David Radford

Support Service Manager

Karen Martin

MND Advisor

Team Leader Eileen O'Loughlen

Team Sue Donaldson,

Jo Fowler, Michelle Malouf,

Ana Petrovic, Vicki

Southgate, Sandra

Woolnough, Ruth Yuthok

Coordination of Support

Team Leader Alexandra

Matouk

Team Cathy Amatya,

Jasminka Gojkovic,

Lauren Lovegrove,

Samantha Potter, Marnie

Roelink, Kristie Stamford,

Rosemary Tome

Information Line Advisor

Kelly Carr

FlexEquip

Team Leader Maree Hibbert

FlexEquip Assistants

Steve Miholic

Nicole Smith

FlexEquip Support Officer

Julie Becke

Education and Carer Support Coordinators

Kristina Dodds

Kate Maguire

Information Resources Coordinator

Penny Waterson

...and many valued volunteers