



In this edition

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A Message from the CEO

It has been a hectic two months on the advocacy front. We have met with senior staff in Aged Care, the National Disability Insurance Agency (NDIA) CEO, Rob DeLuca, and federal Health and Disability Ministers and their advisers. In August we will meet again with the NDIA and My Aged Care management to discuss recurrent issues with both systems. The following month we are meeting with the NDIS Senate Committee for a private hearing. Making these systems work for all people is slow going and changes/improvements are incremental not dramatic. It is not too late for you to let NSW politicians know of the good, bad and the ugly of the NDIS implementation. Find out how to lodge a submission on page 2.

I encourage you all to take part in one or more of our upcoming Walks to d'Feet MND. The Walks raise not only much needed funds but also help raise awareness and show all people with MND that they are not alone. A full list of Walks can be found on page 5.

Graham Opie



Living Well with MND Information Day

15 August, Woden, ACT
25 September, 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>.



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](#).



Have your say to the NSW parliament about the NDIS

The New South Wales state parliament is holding an inquiry into the NDIS and disability in NSW. They want to hear about peoples experience with the NDIS and we encourage people with MND to contribute. Whether you are having a good experience or a bad one, we all need to make sure our voices and stories are heard. Submissions close Thursday 9 August 2018. [Find out more here](#).



Sydney Hawks 2018 Charity Day

The Sydney Hawks Supporter Group Charity Day was a great success raising over \$1,300 for MND NSW. In addition to the game day viewing there were delicious cup cakes and biscuits for sale, competitions, a raffle and silent auction.

Thank you to the Sydney Hawks Committee (pictured right) for their support. Special thanks to Ruth Langdon who was a coordinator of the day to support our Association. Ruth said of the event, "We are all so grateful for the opportunity to make a contribution to such a wonderful cause."



Plunkys Ride for MND

A big thank you to Steven Plunkett and his daughter Rebecca who organised 'Plunkys Ride for MND', a fun cruise by bike and car to help create awareness and support for MND NSW. Steven's love of motor bikes inspired the event. The ride started at Ourimbah rest stop then continued around Lake Macquarie and finished at Caves Beach. Despite the rain the day received great support and raised \$3,180. Thank you Steven and Rebecca.

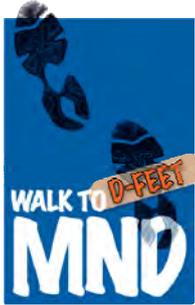


Holy Spirit School, Lavington

A big thank you to the teachers and pupils of Holy Spirit School in Lavington who recently raised over \$2,000 for MND NSW with an ice bucket challenge. A special mention to Jordan Delaney who individually raised \$700 towards this total, pictured right completing the ice bucket challenge. Thanks Jordan, love your MND NSW T-shirt.



Wrapping up Walk to d'Feet MND Penrith Sunday 15 July at International Regatta Centre, Castlereagh



Another wonderful Walk to d'Feet MND completed, our first in Penrith and what a fantastic result. Over 400 participants and currently \$30,514 raised. Thank you Penrith.

What a lovely venue, fantastic atmosphere and a very enthusiastic crowd. A big thank you to Kath Cavanagh and Team Jean for their wonderful support for this event.

Thanks to Rod, Murray and Milton for their great music, the Rotary Club of Penrith for the yummy food and Mel from Cafe2U for the amazing brews. Last but certainly not least a big thank you to our wonderful volunteers and to everyone who came and supported this event. See you next year, we will certainly be back.

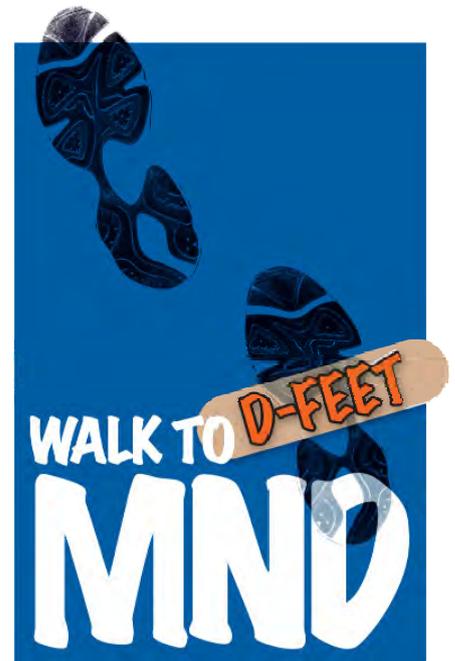
Supported by



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 26
Aug

Walk to d'Feet MND Batemans Bay *Supported by*
Corrigans Beach Reserve, Batehaven

Register now



Sun 16
Sep

Walk to d'Feet MND Port Macquarie *Supported by*
Westport Park, Port Macquarie

Register now



Sat 13
Oct

Walk to d'Feet MND Wagga Wagga *Supported by*
Apex Park, Wagga Wagga

Register now



Les Gray Plumbing



Sun 4
Nov

Walk to d'Feet MND Sydney *Supported by*
Blaxland Riverside Park, Olympic Park

Register now



Well done Shailee

Thank you to a special young lady, Shailee Sullivan, who gave her time before school each morning during the last week of June with a fundraising and merchandise stall for MND NSW. Shailee's fundraiser was a great success and she raised a fantastic \$1,000. Thank you also to the Umina Beach Public School community who gave their support. Congratulations Shailee!



Young Carer Bursary Program

Carers Australia Young Carer Bursary Program offers 12 month scholarships of \$3000 to 333 young carers who are currently studying. Apply for the 2019 bursary online before 5pm, 5 September 2018. More info here <http://youngcarers.net.au/young-carer-bursary-program/>

Past Carers Lunch

Twice a year MND NSW holds a lunch at our centre in Gladesville, for those who have cared for someone with MND and experienced bereavement during the past 12 months. Those who have previously attended one of these luncheons tell us that they found it beneficial to meet with others who understand MND. The next lunch will be held on 17 September. [Learn more and reserve your place.](#)



If you are unable to attend this get-together yet would like to connect with others and gain support, Carers NSW is currently taking expressions of interest for their next therapeutic Grief and Loss Talk-Link telephone support group. This telephone group is facilitated by counsellors and runs for an hour weekly for six weeks. To register your interest call the Carers NSW Carer line on 1800 242 636.

Information Evening

If you or someone close to you has been recently diagnosed with MND, this evening will provide an opportunity to have some of your questions answered in an informal setting. The next Information Evening is on 14 August at the MND NSW Gladesville Centre. There is no charge for you to attend but you will need to reserve your place. [Learn more and reserve your place.](#)



FlexEquip equipment

During 2017-18 FlexEquip provided 1813 equipment items to people in NSW and the ACT. If these items were purchased by these individuals they would cost more than \$2.3 million! In addition, FlexEquip incurs repair, maintenance, delivery and return costs of these items. Not included in this total is the hire cost of 10-12 beds per month for people in regional/rural areas. Items shipped included:



- 139 iPads preloaded with communication apps.
- 127 electric lift armchairs
- 117 manual wheelchairs
- 103 pressure care mattresses
- 85 power wheelchairs
- 68 homecare beds
- 65 hoists

Due to demand on stock FlexEquip also purchased 197 new equipment items during the year costing just over \$188,300 including beds, iPads and hoists.

We could not fund the FlexEquip service without the efforts of our generous and dedicated supporters who do the walks and plan, run and attend events to raise funds for MND NSW. Thank you for your support.

Luskintyre Air Field Family Fun Day

A big thank you to the Rotaract Club of the Hunter who raised \$6,500 for MND NSW at their Luskintyre Air Field Family Fun Day! After a lot of work by the Club the day was a great success with the highlight being Tiger Moth plane and helicopter joyride flights (see cover). The day also included stalls, kids activities, a bake sale and sausage sizzle. Thank you to everyone who attended and supported the event.



Fundraising Weekend in Singleton

The K-Farm Family Fundraising Weekend in Singleton was held during April with a fantastic \$4,166 raised for MND NSW. A big thank you to Nigel and Cynthia Korff, and everyone who assisted in organising the event. It was a very successful and enjoyable weekend. Thanks also to everyone who attended and gave so generously.

We appreciate your support

2018 has already seen many community events held across NSW and ACT. Special thanks must go to each and every organiser who gave so generously of their time to raise funds for MND NSW and awareness about MND. Thank you to the following supporters:

- Crestwood Public School in Baulkham Hills for raising \$1,355 for research from their MND Day 2018.
- St Mary's Primary School in Warners Bay held a MND NSW merchandise stall over two weeks and raised \$2,820.
- Kimberly Chamberlain who organised a 5K Walk in Memory of Garry Davis raising \$582.
- Vicki Gulaptis and the community of MacLean who donated \$1,612 from their Dance Night.
- A donation of \$474 from a morning tea held at the Quirindi Retirement Home, organised by Delores Nankivell.
- Sonia Thornberry and the staff at Norwest Commercial Real Estate who donated \$332 from their MND Soup Fundraiser Day.

Upcoming community fundraising events

- 12
Aug

St Ives AFC Girls Footy Fights MND
St Ives


- 2
Sep

Bowls Day
Tuggeranong ACT
- 5
Oct

Giving MND the Chop
- 7
Oct

Bunnings Sausage Sizzle
Eastgardens
- 13
Oct

Gundaroo Music Festival 2018
Gundaroo Park


- 29
Nov

Dave Matthews Seniors Tennis Tournament
Nelson Bay

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

Applications now open for new MND Research Innovator Grants for 2019

MND NSW contributes your donations towards MND research to the MND Research Institute of Australia (MNDRIA) for competitive peer reviewed grant distribution to researchers who can demonstrate the 'best' chance of finding a cure for MND, advance understanding of the causes of MND and enhance MND clinical research. You can [make your donation to MND research here](#). For researchers, applications are now open for new MND Research Innovator Grants for 2019 and more from the [MNDRIA](#).



Education and MND Aware training 2017-18 across NSW and the ACT

In July 2017 we travelled to Wagga Wagga with our flagship MND Aware face-to-face training for health and community care professionals. Some 16 allied health professionals



from Wagga Wagga, Griffith, Albury and Lockhart attended, all with an interest and passion for working with people living with MND in their areas.

In August 2017 we held our bi-annual Special Interest Group Workshop for allied health and community care workers at West Ryde with 140 attending.

We conducted our Living Well with MND one-day program at Ryde in September 2017 and there was great interest in our Living Well with MND Day in the Illawarra in October 2017 with 55 people attending.

In November 2017 we held a two day residential workshop in Cowra for carers of people living with MND with 20 family carers attending from central west and southern NSW and Canberra.

MND Connect, a day for people with MND, family and friends, focussing on research and MND was held at Sydney University in November 2017.

In 2018 we kicked off the year with six workshops for health professionals and care providers on supporting people living with MND who are NDIS participants in geographic areas new to the NDIS roll-out including the Illawarra and the inner west, east and southern Sydney areas, with a total 192 attendees.

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In March 2018 we presented the Living Well with MND program at Bossley Park. In May 2018 we headed north of the State conducting two days of workshops in Port Macquarie and a day for people living with MND on the Gold Coast. Also in May 2018 we held our annual Care for Carers four-week program at Gladesville.

At all of the above events we have collaborated with medical and allied health professionals and team members from nearby health and community services. This takes a lot of organising but does provide an opportunity for attendees to link up with other 'locals'.

We are heading off to Canberra in August to run a Living Well with MND Day in Woden. We still have places available for this event on 15 August, so please contact us if you would like to attend. It is for people living with MND, their family and friends. No matter where you live, you are welcome to attend this day if you happen to find yourself in Canberra, or if Sydney is closer, the Living Well with MND Day at West Ryde on 25 September.

What have *you* learnt that has made living with MND a little easier?

Kelly Carr or Kate Maguire at the MND NSW Info Line infoline@mndnsw.asn.au would love to hear your tips and tricks, so we can share them with others.

Can you help us save some postage costs?

The MND NSW e-news is issued every month or so and compiled into a condensed print version every quarter as MND NSW *News* (formerly *Forum*). Let us know if we can remove you from the print *News* list.

Unlocking the mystery of motor neurone disease

Listen to 'Unlocking the mystery of motor neurone disease' episode from *Conversations*, presented by Richard Fidler-Sarah Kanowski broadcast on 30 July 2018 and featuring Professor Dominic Rowe from Macquarie University at <http://www.abc.net.au/radio/programs/conversations/conversations-dominic-rowe/10027340>



Upcoming Support Service events

Click to find out more.

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.

TEALS Study update

Researchers will be recruiting 90 people across NSW, QLD, SA, WA and VIC who meet the criteria for enrolment to participate in the TEALS Study - a multi-centre Phase 2 clinical trial to investigate the safety, tolerability and effectiveness of a drug dimethyl fumarate (trade name Tecfidera) in people with MND.

Source: National Health and Medical Research Council

The study to Assess the Efficacy and Safety of Tecfidera in Patients with Amyotrophic Lateral Sclerosis (TEALS) Study ID ACTRN12618000534280.

Key inclusion criteria

1. Male and female patients aged 18 to 85 years at the time of the Screening Visit.
2. Able to provide informed consent and comply with study procedures.
3. Sporadic ALS diagnosed as definite, probable, or possible according to the Awaji criteria as determined by a neurologist subspecializing in ALS.
4. Disease duration at recruitment less than 24 months from diagnosis.
5. Patient must have the results of magnetic resonance imaging scan of brain and spinal cord undergone within 2 years (24 months) prior to the Screening Visit.
6. Forced vital capacity >60% of predicted value as adjusted for gender, height, and age at the Screening Visit.
7. Must be on a stable dose of riluzole for at least 30 days prior to the Screening Visit.
8. Patient who has established care with a neurologist at 1 of the 5 specialised ALS clinics involved in the study and will maintain this clinical care throughout the study.
9. If a patient is referred from a third party (neurologist or a State based ALS organisation) they should be willing to transfer care to the neurologist participating in the study.
10. Patients may participate in clinical registries, but will be excluded if they are participating in a clinical study involving an alternative

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investigational treatment.

11. Women of childbearing potential must have a negative urine pregnancy test at screening and Baseline, and be surgically sterile or postmenopausal, or using highly effective methods of contraception throughout the study and for 30 days after the last dose of IP.

Key exclusion criteria

1. Dependence on mechanical ventilation at the time of screening.
2. Gastrostomy at the time of Screening/Baseline Visit. If the patient has a gastrostomy tube inserted post randomisation they will be allowed to continue in the study.
3. Participation in any other IP study or using an IP (within 12 weeks prior to screening).
4. Known hypersensitivity to Tecfidera or any excipients in this product.
5. Presence of a monogenic cause of ALS (e.g. known mutation in superoxide dismutase-1 (SOD1), expansion in c9orf72 etc.).
6. Taking immunosuppressive medications.
7. Positive test for human immunodeficiency virus (HIV), hepatitis B (+HbsAg), or hepatitis C.
8. Presence of any of the following clinical conditions at the time of screening:
 - Unstable medical disease (such as unstable angina, heart failure, chronic obstructive pulmonary disease, liver disease or renal disease), or active infectious diseases (such as hepatitis B or C or tuberculosis), or current malignancy.
 - Unstable psychiatric illness defined as psychosis or untreated major depression within 90 days of the Screening Visit. This exclusion criteria is based on a prior psychiatric diagnosis that is unstable as determined by the patient's treating Psychiatrist.
 - Dementia as previously diagnosed by a medical practitioner.

Contact person for information and recruitment is Prof Steve Vucic

Department of Neurology Westmead Hospital Ph. 02 9845 6097

steve.vucic@sydney.edu.au. Full trial listing: <https://>

www.australianclinicaltrials.gov.au/anzctr/trial/ACTRN12618000534280

FORTITUDE-ALS study update

Researchers are currently recruiting people from QLD, SA and WA who meet the criteria for enrolment in this multi-centre Phase 2 clinical trial investigating the safety, tolerability and effectiveness of a drug called reldesemtiv (also known as CK-2127107) in people with MND.

Source: National Health and Medical Research Council

The Study to Evaluate Efficacy, Safety and Tolerability of CK-2127107 in Patients With Amyotrophic Lateral Sclerosis (ALS) (FORTITUDE-ALS) Trial ID NCT03160898.

Key inclusion criteria

1. Diagnosis of familial or sporadic ALS = 24 months prior to screening
2. Upright Slow Vital Capacity (SVC) = 60% of predicted for age, height and sex at screening
3. Able to swallow tablets
4. A caregiver (if one is needed)
5. Able to perform reproducible pulmonary function tests
6. Pre-study clinical laboratory findings within the normal range or, if outside the normal range, deemed not clinically significant by the Investigator
7. Male patients who have not had a vasectomy and confirmed zero sperm count must agree after receiving the first dose of study drug until 10 weeks after the last dose to either use acceptable methods of contraception or abstain from sex
8. Female patients must be post-menopausal or sterilized or must not be breastfeeding, have a negative pregnancy test, have no intention to become pregnant during the study and use acceptable methods of contraception or abstain from heterosexual intercourse from Screening until 10 weeks after last dose of study drug
9. Patients must be either on riluzole for at least 30 days prior to screening or have not taken riluzole for at least 30 days prior to screening and not planning to start riluzole during the course of the study.
10. Male and female patients aged 18 to 80 years.

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Key exclusion criteria

1. At the time of screening, any use of non-invasive ventilation (NIV), e.g. continuous positive airway pressure [CPAP], noninvasive bi-level positive airway pressure [NPPV] or noninvasive volume ventilation [NIVV] for any portion of the day, or mechanical ventilation via tracheostomy, or on any form of oxygen supplementation
2. Neurological impairment due to a condition other than ALS
3. Presence at screening of any medically significant cardiac, pulmonary, GI, musculoskeletal, or psychiatric illness that might interfere with the patient's ability to comply with study procedures or that might confound the interpretation of clinical safety or efficacy data
4. Has taken any investigational study drug within 30 days or five half-lives of the prior agent, whichever is longer, prior to dosing
5. Known to have received CK-2127107 or tirasemtiv in any previous clinical trial
6. Has received or is considering receiving during the course of the study any form of stem cell therapy for the treatment of ALS
7. Has received or is considering receiving during the course of the study any form of gene therapy for the treatment of ALS
8. Has received or is considering obtaining during the course of the study a diaphragmatic pacing system
9. History of substance abuse within the past 2 years
10. Use of certain medications

For information and recruitment see <https://www.fortitude-als.com> or contact medicalaffairs@cytokinetics.com. Full trial listing: <https://www.australianclinicaltrials.gov.au/anzctr/trial/NCT03160898>

Find out more and register for updates about clinical trials in Australia at AustralianClinicalTrials.gov.au - a joint initiative between the National Health and Medical Research Council and the Department of Industry, Innovation and Science to provide information and resources to consumers, health care providers, researchers and industry about clinical trials.

Membership satisfaction survey 2018 - Final Report

In May 2018 all MND NSW Support Service members were invited to participate in the 2018 Membership Satisfaction Survey. We undertake this survey every two years as a part of our continuous quality improvement program. It is an opportunity for members to provide feedback about their level of satisfaction with our services

The 2018 survey response rate was 44% (n=246), which is a really great response. The results of this survey show that members highly value the services offered by MND NSW and the staff and volunteers who provide them. They also reveal some areas for further development into the future:

- greater access to education and training in regional areas
- providing news updates in a variety of formats to meet the diverse needs of our MND community
- maintaining the quality and range of our equipment and look at how we can maintain this quality and range when technology continues to change rapidly
- continuing to promote awareness of MND in the media
- working nationally to advocate for the needs of people with MND, particularly those over 65 years who are not eligible for NDIS funding
- maintaining staffing levels so that members do feel supported
- promoting the MND Info Line as an alternative support if the MND Advisor is unavailable
- promoting the availability of education programs for health and community care professionals

Thank you to all who completed this survey. We really appreciate the time taken to complete it. It has given us some ideas for future service improvements and has provided affirmation for us to continue with the programs that are valued highly by our members. [You can read the full report here.](#)

Gina Svolos

Manager Support Service



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...and many valued
volunteers