



In this edition

Get in quickly for Walk to d'Feet MND Sydney on Sunday 4 November 2018 and Ask the Experts Monday 5 November 2018... We need you to help us Make Aged Care Fair for people living with MND... Gundaroo - another successful year... Introducing Karen Martin, Manager, Support Service... Are you an MND Genie?... and more.

A Message from the CEO

In October we welcomed Karen Martin to the Association as Manager, Support Service. Karen has hit the ground running and introduces herself on page 5 of this edition of *e-news*.

Also taking off is our Make Aged Care Fair campaign. Let your MP know that we need to Make Aged Care Fair for people living with MND. Use our online e-action to email your federal MP to raise awareness of the issues people with MND are facing. Read more on page 7.

Online registrations close soon, on Tuesday 30 October, for our Sydney Walk to d'Feet MND to be held next weekend, Sunday 4 November. After online registrations close on 30 October you can still register on the day. However Walk T-Shirts are only available for pre-registered participants who pre-order them. Find the registration link on page 3.

Graham Opie



It's time to register for Ask the Experts

Monday 5 November, West Ryde

Do you want to hear experts speak about MND and what's new in MND research?



We still have places available at our Ask the Experts Forum on Monday 5 November at West Ryde. This Forum is an opportunity for you and your family to bring your questions about MND and have them answered.

There is no charge to attend but you do need to RSVP. Find more information [here](#).

Program

10am	Tea and coffee on arrival
10.30	Welcome - and overview of day
10.35	<p>About Motor Neurone Disease <i>Dr Rebeka Ahmed</i> Consultant Neurologist, Senior Lecturer and Director of the Memory and Cognition Clinic at Royal Prince Alfred Hospital and the University of Sydney</p>
11.15	Question time
11.40	<p>Genetic factors in MND; progress and hopes for familial and sporadic MND <i>Associate Professor Ian Blair</i> Macquarie University Centre for Motor Neurone Disease Research</p>
12.15pm	Question time
12.30	Lunch
1.15	<p>Getting involved - MND research and clinical trials <i>Dr Shyuan Ngo</i> Scott Sullivan MND Research Fellow at the University of Queensland</p>
2.00	Question time
2.20	Closing address

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

Don't miss out on our last Walk to d'Feet MND for 2018. Join in the fun at Walk to d'Feet MND Sydney on 4 November! Online registrations close 9am Tuesday 30 October.

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.



Sun 4
Nov

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

[Register now](#)

Supported by



You are invited - Members' Christmas Party

Saturday 1 December, West Ryde

Come along to our afternoon Christmas Party at West Ryde on Saturday 1 December to celebrate the beginning of the festive season with MND NSW.

It would be terrific to see you, your family and friends there! Santa shall be taking a quick break from the North Pole to visit with gifts for the children. Adults will have a chance to win a lucky door prize or to win one of the great raffle prizes. RSVP by 26 November. [For more information and to reserve your place, click here.](#)



Next Information Evening - Tuesday 4 December

Our next Information Evening for people recently diagnosed with MND, their family and friends is on Tuesday 4 December at the MND NSW Centre Gladesville. More info [here](#).



Newcastle Italian Film Festival

9, 10, 11 NOVEMBER 2018

Tower Cinemas, 185 King St, Newcastle

BUFFAIO CHEESE (Burrodoc Farm), WINE (Angove Wines), PIZZA (Napoli Centrale), ITALIAN DOLCI (The Umbrian) will be on offer to our paying film festival patrons on opening night Friday and Saturday night from 6pm

The Dino and Anna Cesta Memorial Scholarship will be awarded on opening night.

From Naples With Love (All Ages)
(Troppo Napoletano)
Friday, 9 November 2018 - 7pm

Daughter of Mine (18+)
(Figlia Mia)
Saturday, 10 November 2018 - 2pm

Sea Dreaming Girls (15+)
(Funne - Le Ragazze Che Sognavano il Mare)
Saturday, 10 November 2018 - 4pm

Ignorance is Bliss (M)
(Beata Ignoranza)
Saturday, 10 November 2018 - 7pm

It's The Law (M)
(L'ora Legale)
Sunday, 11 November 2018 - 2pm

Suburra (R18+)
(Suburra)
Sunday, 11 November 2018 - 4pm

Life is Beautiful (PG)
(La Vita E' Bella)
Sunday, 11 November 2018 - 7pm



facebook.com/NewcastleItalianFilmFestival

SINGLE TICKET ADMISSION: \$15
Single Concession Admission: \$13*

*Eligible Concessions: Newcastle Film Society members, full time students, seniors and pensioners. Proof of concession must be presented.

MULTI FILM PASS

4 FILM PASS - General Admission: \$48; Concession: \$44*

7 FILM PASS - General Admission: \$70; Concession: \$63*

Advanced bookings recommended, particularly Opening night and Saturday night sessions. All ticket prices are GST inclusive.



TOWER CINEMAS
NEWCASTLE

Tickets can be purchased at TOWER CINEMAS NEWCASTLE, either at the Newcastle King Street box office, or on-line** at www.eventcinemas.com.au. For further information, contact (02) 4926 2233.

** Online bookings incur a \$1.40 booking fee.

Support Services Update

My name is Karen Martin and I recently joined MND NSW as Manager, Support Service. It is my privilege to lead a professional and committed team offering an exceptional range of services for people living with MND.



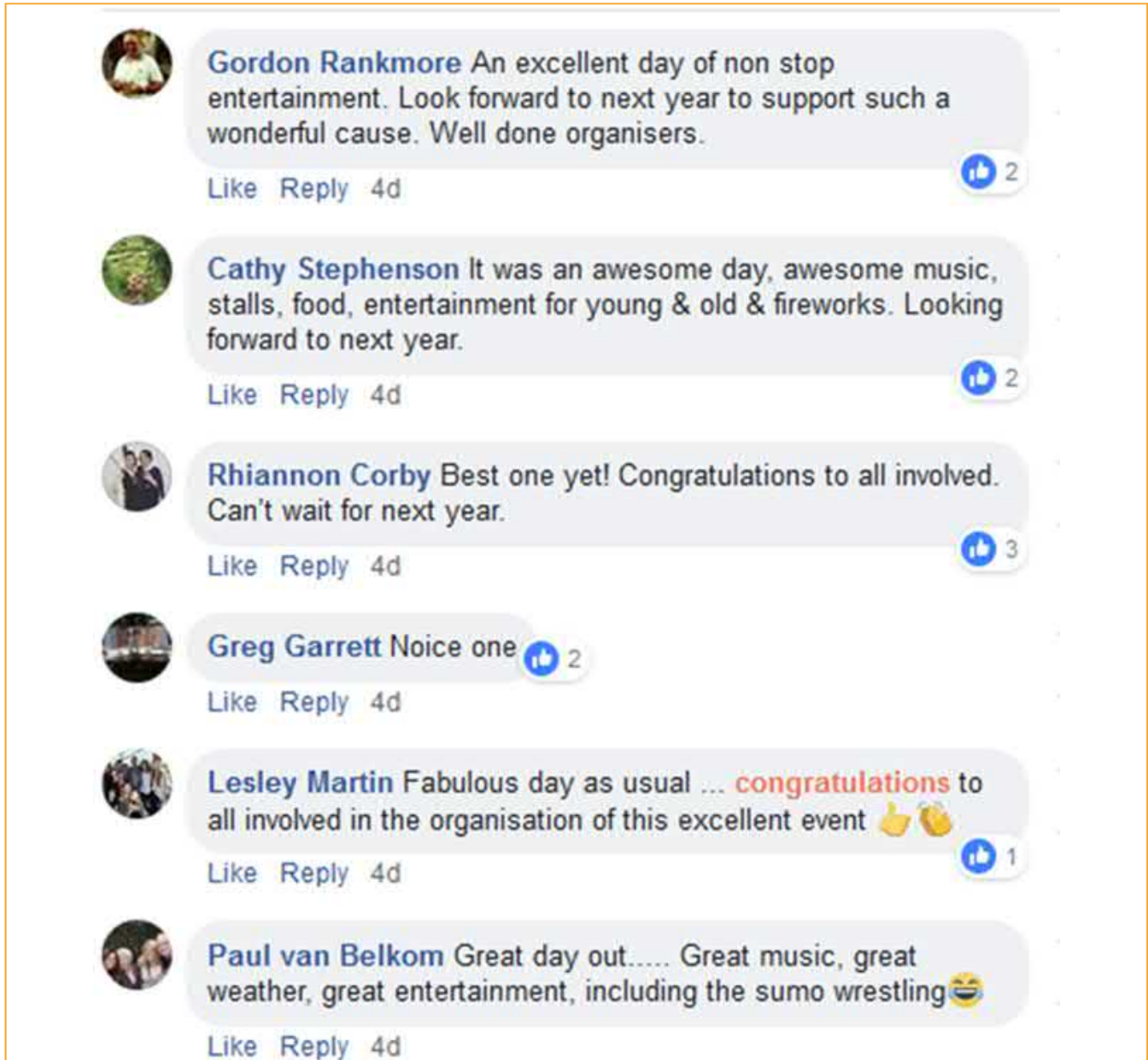
At MND NSW we are continually looking for ways in which to improve and extend our services. As such, we have now extended our Coordination of Support (COS) to offer a statewide service. This means that people across NSW with MND looking to implement their NDIS plan can now access the specialist MND knowledge that our COS team offer. For all people with MND in regional and remote areas the service will be offered as a phone based service, with access to video conferencing when available. An MND NSW COS will assist people with MND to understand their NDIS plans, set up services as well as access funded supports. For more information or to refer a person with MND to this service contact Alexandra Matouk, Team Leader, Coordination of Support ph. 02 8877 0935 or AlexandraM@mndnsw.asn.au.

A little about me - I have worked within the aged, disability and community sectors for over 20 years and recently completed studies in psychology, dementia care and gerontology. More importantly I have been the primary carer for my son and joint carer for my parents and sister. The latter giving me a good understanding of what it is like to need services but not be able to find them! I was particularly drawn to MND NSW because my father lost his mother (my grandmother) to MND at a relatively young age and I am acutely aware of the impact this had and continues to have within our family.

I am very much looking forward to being of service to our MND members and wider community.

Karen Martin
Manager

Goulburn Toyota GUNDAROO MUSIC FESTIVAL



The 2018 Goulburn Toyota Gundaroo Music Festival held on 13 October was delivered with fantastic reviews from those who attended. Thank you to the wonderful sponsors and enthusiastic volunteers. There were amazing displays, great stalls, great acts and great people which, together with the lovely weather, made for a terrific family friendly day out. A very big thank you to Scott Harding and his amazing team who work so hard to bring this great day together to raise funds for people living with motor neurone disease.

MND Connect - 10 November at the University of Melbourne

The 4th annual MND Connect Forum for the MND community will be held in Victoria on 10 November. People living with MND, their friends and family as well as the broader MND community are invited to attend this interactive forum connecting people impacted by MND with Australia's leading MND researchers. Find out more about MND Connect 2018 [here](#).



Make aged care fair - let your MP know

People diagnosed with MND when aged 65 or over are not getting the care and support they need. Join the campaign and help us end this inequity.

Let your MP know that we need to Make Aged Care Fair for people living with MND by using our online e-action to email your federal MP to raise awareness of the issues people with MND are facing and call on Government for changes to Aged Care. [Take action now and ask your MP to Make Aged Care Fair for people living with MND.](#)



Thank you Ballina Arts and Crafts Centre

A big thank you to the members of the Ballina Arts and Crafts Centre, Inc (BACCI) who generously donated \$1,000 to raise awareness and help to purchase equipment for MND NSW. BACCI is a non profit organisation and consists of a group of creative artisans who enjoy displaying their artwork in a group, while having fun along the way! BACCI held their annual Spring Exhibition in Ballina during September, and the group decided to choose MND NSW as their fundraising charity. Pictured (L-R) Deb McFarlane and Mary Richards.



MND NSW Christmas Cards

Support MND NSW with the purchase of our Christmas Cards. There are three lovely new designs this year. Purchase your cards by contacting the MND NSW Centre at Gladesville ph 02 8877 0999 or online [here](#).



Christmas Puddings by Pudding Lane

Our wonderful Pudding Lane puddings are back. Get yours today! We have limited stock so don't miss out. Orders can be placed by contacting the MND NSW Centre at Gladesville ph 02 8877 0999 or online [here](#).



Celebrating MND carers in the Northern Rivers

The rain had been pouring down in the Northern Rivers for a week but it didn't stop our MND families meeting up to celebrate Carers Week 2018 at a scrumptious morning tea on 15 October in Alstonville. Thank you Carers NSW for partnering with MND NSW so we could celebrate our carers and enjoy good company.

Upcoming Support Service events

Click to find out more.

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

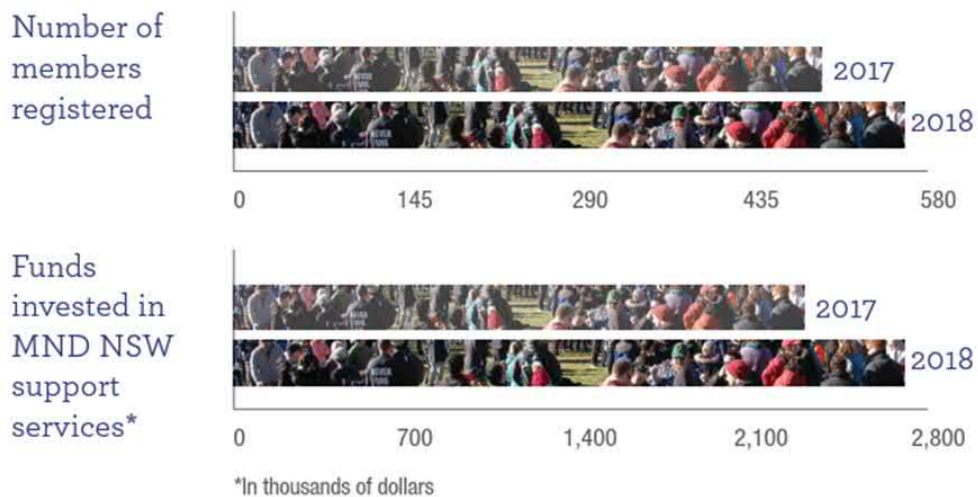
MND support groups and coffee mornings



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.

We continue to need your support

The services we offer and our ability to advocate on behalf of people living with MND and their families relies on the financial support provided by our supporters. If you would like to be part of the change needed by providing a donation of any size, at any time, then please visit the [DONATE](#) page on our website www.mndnsw.asn.au. For larger donations, corporate giving or bequests please speak with our Supporter Liaison Officer, Yvonne Hamilton ph. 02 8877 0927 or YvonneH@mndnsw.asn.au.



Upcoming community fundraising events

Click to find out more.

- 9-11
Nov

Newcastle Italian Film Festival
Tower Cinemas Newcastle


- 16
Nov

Newcastle Royals Korfbal Club Trivia Night
Charlestown Bowling Club


- 29
Nov

Dave Matthews Seniors Tennis Tournament
Nelson Bay
- 2
Dec

MND Fundraising Garage Sale
Berry

MND Genies

Sisters Jessica and Kaitlin felt so lost having just lost their mother to MND. The fact that both sisters had been identified as carrying the same MND related genetic mutation as their mum, on the C9ORF72 gene, became a prominent thought.



Rebecca, Kaitlin and Jessica

For Jessica and Kaitlin, every little weakness triggered a thought that it was a sign of MND starting and they would have to go through it all and miss out on the rest of their young lives. They were on a lonely emotional roller-coaster, while trying to get on with their lives.

One day Kaitlin was at a training day for work where she was asked to make a vision board about a future goal in their life. Kaitlin decided that her life goal would be to never get MND, despite the statistics and odds. She explained her story to a few in the class. After class a girl who overheard the explanation approached Kaitlin and mentioned that a friend of hers was going through something similar. Would she mind if she put them in touch? Of course Kaitlin said yes. They were looking for someone who fully understood what they were going through. Yes, they had family and friends supporting them, but it wasn't what they needed.

And then the sisters met Rebecca and they all instantly hit it off. They talked for hours and while their stories were different they could relate to each other. Rebecca has the SOD1 gene in her family and lost her father when she was younger but still carries the scars of this disease every single day.

"The idea of MND Genies (see next page) came about as there are supports and trials available for people who currently have MND, but for those with the genes it's like they are sitting ducks waiting for the gene to activate with no support available. Just knowing someone who is in the same boat as you can make the world of difference. It has for us three and now we'll be friends forever."

Jessica, Kaitlin and Rebecca



Are you, or is a person in your family, an MND Genie?

MND Genies is a closed unlisted Facebook group for people, living in Australia or New Zealand, who have a motor neurone disease related genetic mutation, but do not have MND.

About 10% of people diagnosed with MND have a familial form of the disease. Of these, about one in five have a mutation on the SOD1 gene and about two in five have a mutation on the C9ORF72 gene. These mutated genes can be passed down through families and children can inherit the mutated gene.

The aim of MND Genies is to provide a forum for group participants to connect with each other and share their knowledge and experiences with others who have an MND related genetic mutation. MND NSW does not endorse comments or posts made by group participants.

To join MND Genies or for more information about the group contact Kate Maguire MND NSW at mndgenies@mndnsw.asn.au or ph. 02 8877 0902.

Note - People diagnosed with MND are not eligible to join or continue to participate in the group and will be offered support through other MND NSW services and programs.



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

PATRON His Excellency General The Honourable David Hurley AC DSC (Ret'd),
Governor of New South Wales

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

AUDITOR Walker Wayland NSW

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Penny Waterson

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Team Chris Carroll, Sue

Donaldson, Jo Fowler,

Michelle Malouf, Lauren

Maxwell, Ana Petrovic,

Vicki Southgate, Ruth

Yuthok

Coordination of Support

Team Leader Alexandra

Matouk

Team Cathy Amatya,

Jasminka Gojkovic,

Lauren Lovegrove,

Samantha Potter, Marnie

Roelink, Kristie Stamford,

Rosemary Tome

Admin Assistant NDIS

Brenda Smith

...and many valued volunteers