

e-news September 2017



In this edition

MND Connect 2017 in Sydney... Aged Care Advocacy... NDIS Pre-Planning Resource... What is Coordination of Support?... Register now for Living Well with MND Ryde and Wollongong... Mike and the Gundaroo Music Festival... Talk-Link Carer Program... Walk to d'Feet MND... and more

A Message from the CEO

Welcome to another MND NSW *e-news*. The *e-news* has proved to be very popular and we've found it a great way of getting information to people in a timely manner.

Suddenly it's the second half of 2017 and the National Disability Insurance Scheme (NDIS) is in to its full roll out. If you are contacted by the NDIS or are eligible make sure you speak to your MND Advisor. Being prepared is the key to a good NDIS Plan. Read more on page 6.

We recently met with the Department of Health and Aged Care in Canberra to help streamline the process of being accepted into My Aged Care (MAC) for those people 65 years and older with MND and we'll have further information in the next *e-news*.

This *e-news* has some great community fundraising stories. Our next Walk to d'Feet MND is in Port Macquarie on Sunday 17 September. All our Walks can be found on page 4. See you at a Walk near you.

Graham Opie





MND Connect 2017 @ University of Sydney 11 November 2017









MND CONNECT 2017: Register now!

Connecting people impacted by MND with Australia's leading MND researchers

Saturday 11 November, University of Sydney www.mndaustralia.org.au/MNDConnect

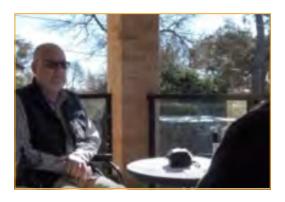




Do you want to know what's new in MND research, current clinical trials and effective treatments for MND? Reserve your place at MND Connect, an interactive forum connecting people impacted by MND, with Australia's leading MND researchers. In 2017 this Forum will be held at the University of Sydney. People with a disability and their carers may reserve a disabled parking spot at the venue, or receive a wheelchair taxi voucher or subsidised travel from a regional area to attend this event. Find out more about MND Connect 2017 here.

Gundaroo Music Festival

Thank you to the hard working committee of the Gundaroo Music Festival for your amazing support. If you haven't attended a Gundaroo Music Festival don't miss this year's event on Saturday, 14 October 2017. Tickets are now on sale at http://bit.ly/2s24Bay. People like Mike, who



have been affected by MND, benefit greatly from the funds raised every year. https://www.youtube.com/watch?v=ddB4Kdizmv0



Are you a Carer in the ACT?

Are you one of the 46,000 Canberrans who provides assistance to people living with disability, chronic health problems, mental



health issues, are frail aged or are in foster or kinship care? If so then Carers ACT really want to hear from you about what would make Canberra a more carer friendly place that supports you and helps you to reach your goals.

Carers ACT has been asked to collect the views of as many carers as possible in order to provide information to help shape the formation of an ACT Carers Strategy. If you are a carer or know a carer, have your voice heard and shape this crucial document. For more information or to share your thoughts visit www.carerstrategy.org.au

National Aged Care Advocacy Program

The Older Persons Advocacy Network (OPAN) provides free, confidential and independent advocacy support to older people who are receiving or seeking to receive Australian Government funded aged care services. The service focuses on supporting older people and their representatives to raise and address



issues relating to accessing and interacting with Commonwealth funded aged care services. More info here http://www.opan.com.au/advocacy/

Woden Valley Gymnastics Club

Thank you to the Woden Valley Gymnastics Club in Canberra who donated \$654 from their recent Pyjama and Teddy Bear Week. Pictured are the coaches from the club. A big thank you to everyone who participated and provided their support.





Walk to d'Feet MND

The name of this event reflects the hope and inspiration these special days provide for the MND Community. 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 MND. You can create your own online fundraising page to raise funds in an individual name or a team name.

17 Sep Walk to d'Feet MND Port Macquarie Westport Park

Register now



15 Oct Walk to d'Feet MND Wagga Wagga Apex Park

Register now





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

Register now





Walk to d'Feet MND Batemans Bay

20 August, Corrigans Beach Reserve



What a great turnout in Batemans Bay for our first Walk to d'Feet MND. A big thank you to our local co-ordinator Victoria Haberley who was motivated to organise this Walk by her friend Sharon Penman.

A beautiful sunny morning greeted the walkers and, after a bit of a warm up exercise to some

great background music, they headed off towards Bateman's Bay. Thank you to everyone who supported this great new Walk and we look forward to catching up next year.



Have you registered yet for the Port Macquarie Walk Sunday 17 September?

This will be our sixth Walk in Port Macquarie and what a lovely Walk it is. There is a great sense of comradery at each of our Walks as they continue to grow and raise awareness and funds for people living with MND. Walk to d'Feet MND Port Macquarie is 5.5km and an easy walk on a concrete path, making it wheelchair and pram friendly. Don't forget to bring the family pooch and register him or her to receive a doggy bandanna. Early bird <u>registration</u> for the Walk closes 10 September, so don't miss out.

If you don't feel like a sea change, why not a tree change?

Join us for the Walk to d'Feet MND Wagga Wagga Sunday 15 October and enjoy the amazing rural setting and hospitality provided by the hard working local volunteers who organise this Walk. The Walk is around the picturesque Lake Albert, which is a fantastic venue. If you have never visited Wagga Wagga you don't know what you are missing. Join us for a sausage sizzle after the Walk or bring along a picnic and enjoy some of the lovely picnic spots on the Lake. Early bird <u>registration</u> will close on 8 October, get your registration in early.

A fundraising event with a difference

If you have ever fancied yourself in a
Bollywood film, this is the event not to be
missed. Navratri Garba 2017 is on Saturday 23
September at Bernie Mullane Complex,
Kellyville. Navratri Garba is an Indian
traditional form of dance performed by millions
of Indians around the world during the



Navratri festival, signifying the Cosmic Energy in the form of Mother Goddess's win of good over evil. People from all ethnicities enjoy the live folk dance and music. This is an alcohol free family day with lots of fantastic dancing and music. Tickets are only \$10 per head with children under 5 free. Money raised from this event supports the work of MND NSW. More info here.



National Disability Insurance Scheme (NDIS) Update

Gina Svolos - Manager, Support Services

The NDIS has now rolled out across NSW and the ACT and many members under 65 years of age have been contacted by the National Disability Insurance Agency (NDIA) who administers this Scheme. If you are under 65 years and have not been contacted we suggest that you contact the



NDIA directly to register for the NDIS on 1800 800 110. Further information is available at www.ndis.gov.au

Our MND Advisors have been working with members to assist them with preparing for their Planning Meeting with the NDIA representative.

Your MND Advisor can assist you by informing you of what to expect at the Meeting and what to consider when thinking about your needs and what you may need included in your NDIS Plan so that when you attend the NDIS Planning Meeting you will feel prepared.

Where possible, the MND Advisor is also able to attend the Planning Meeting with you either in person or over the phone.

We have a Pre-planning
Resource Pack that we can send
to you and our staff can go
through this over the phone or in
person as part of this
preparation process.



Pre-Planning Resource Motor Neurone Disease



For people living with motor neurone disease



This Planning Resource is designed to assist you identify the areas of your life the NDIS will need to consider when developing your NDIS Plan.

(Continued on page 7)



(Continued from page 6)

In this document we suggest that when you are contacted by the NDIS Planner or Representative, such as a Local Area Coordinator (LAC), to arrange your Planning Meeting or information gathering session, we strongly recommend the following actions:

- Advise them immediately that you have motor neurone disease and ask if they have an understanding of the condition (they may not).
- Ask for your Planning Meeting to occur face-to-face. You do not have to accept a phone meeting; this is not usually effective for people with MND.
- If applicable, advise them that you have High Medical Support Needs and ensure that they understand that before commencing the Planning Meeting.
- Contact your MND Advisor, they can assist with additional Pre-Planning and may be available to attend your Planning Meeting, though this is not always possible.
- Prepare for your Meeting. Our Pre-Planning Resource will assist you in your preparation.
- Please contact your MND Advisor or our MND Info Line on 1800
 777 175 to request a copy of this Pre-planning Resource Pack.

FlexEquip Service

For NDIS participants it is important that your assistive technology equipment is included in your Plan and if you select FlexEquip as your service provider then the MND NSW Equipment Service, FlexEquip, will be able to continue to provide this equipment as required.



Your MND Advisor is able to give you a list of your current equipment to give to the person doing your Plan so that this can be included in your Plan.

(Continued on page 8)



(Continued from page 7)

Coordination of Support Service

MND NSW also have Coordinators of Support available to members living in Sydney Metropolitan area, Illawarra, Central Coast and Newcastle areas, to assist you to implement your NDIS Plan.

This service is one of the supports that is funded under the NDIS if you include it in your Plan.

Through this service we can assist you to ensure your Plan runs smoothly and efficiently and help you to find other services that can assist you.

As our Coordinators of Support work at MND NSW they have knowledge about MND and are well-placed to work with you to

Coordination of Support



for people living with motor neurone disease

Our Coordination of Support
Service can assist you with the implementation of your National Disability Insurance Scheme (NDIS) plan.

We have knowledge and expertise in the **Coordination of Support** for people living with MND.

implement your Plan with the understanding of what people living with MND may need.

MND NSW continues to advocate for the needs of people with MND and we meet with the NDIA to provide feedback about the experience of people with MND under the NDIS so please contact us if you would like to provide any feedback on how this experience has been for you.

For Sale

2004 Volkswagen Caravelle V6 T4 Auto, reg. to Feb 2018. 381,191km. Red with Professionally installed RICON S-Series Electric-Hydraulic Wheelchair Lifter in excellent working condition. \$13,999. Woy Woy Bay. More info here https://www.carsales.com.au/private/details/Volkswagen-Caravelle-2004/SSE-AD-4867253/



Introducing our new staff... Jody Kildey | MND Advisor

I have recently joined the team at MND NSW as MND Advisor for the Newcastle, Central Coast and mid North Coast areas. My background includes nursing, case management and service coordination. More recently I have worked in the retirement village sector supporting the aged to



remain independent within their homes. I am looking forward to working with the team at MND NSW and getting to know our members and their families.

Living Well with MND Information Day

12 September at West Ryde

17 October at Wollongong

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.

Our new Bucket Hats have arrived

For those that prefer their hat with a bigger brim we now have new bucket hats in stock in two sizes, Small/Medium and Large/XL. Visit www.online.mndnsw.asn.au and order your hat today!





City2Surf

Congratulations and a big thank you to all of our participants in the recent City2Surf. 26 eager MND supporters from as far away as Newcastle, Canberra and Cooma lined up early Sunday morning to face the gruelling run from the City to Bondi Beach to raise funds and awareness for Motor Neurone



Disease. What a fantastic job they did raising over \$24,000.

Pictured are MND NSW supporters Shelagh Hayman and friends (top), and three of the competitors from our City2Surf Superstars Team, Liz, Mary and Clare (right). A special thank you also to Team Cooma (pictured on the cover of this *e-news*) who marked their fifth year of raising funds in the City2Surf for



MND NSW. We greatly appreciate the many runners who participate in this event year after year.

James Sheahan Catholic High School

Thank you to the students and teachers at James Sheahan Catholic High School, Orange. Our local ambassador Nicole attended a school assembly for the recent cheque presentation. The student representative coordinator Winston West told



us "At the beginning of each year, the SRC decides on a local, national and international charity to raise money for during the year. The national charity that they decided upon was MND NSW. As a group, we decided to hold a 'mufty' day where students wore blue to support MND and brought in a donation to go towards research. As a school community, we have many families who are coping with MND and so we thought it was a very relevant and important cause to raise the money for. As a school we raised \$1,430 which has now been donated to MND NSW."



University of Oxford videos about inherited/familial MND

Videos of the MND education day held in April at the University of Oxford, about inherited/familial MND are now available and cover Genetics and MND, Genetic Testing and Research on Family Members. Watch free online https://



mndresearch.wordpress.com/2017/08/02/

more-information-for-families-affected-by-inherited-mnd-available-online/

An Ice Bucket Challenge in Canberra

Gold Creek School in Canberra, an International Baccalaureate school, hosted their first student organised ice bucket challenge. As part of her Personal Project, Year 10 student Lydia Elliott organised the challenge to fundraise for MND. On a cold winters day 12 brave teachers volunteered to have a bucket of ice cold water poured over their heads. Students donated \$428 for the pleasure of seeing their teachers suffer. On the day 12 students, who had donated, had their names drawn from a list for the honour of pouring the water while the whole school watched on. Thank you to the teachers and students of Gold Creek School!





West Social Golf Club Charity Day

Thank you to the West Social Golf Club from Newcastle who generously donated \$1,000 from a recent charity day. Pictured is Michael Pearce, Club Secretary, and Patti Conway, MND NSW Ambassador, accepting the donation on our behalf. Thanks also to everyone who supported this event.





Upcoming Support Service events

Click to find out more.

Living Well with MND
West Ryde

18 Past Carers Lunch
Gladesville

Information Evening for people recently diagnosed with MND
Gladesville

Living Well with MND
Wollongong

Talk-Link Carer Wellbeing Program by telephone
Six-week telephone program for adult carers, facilitated by
professional counsellors

Link and Learn

A residential educational workshop held over two days and one night for carers

Cowra

MND Connect 2017

Community, researchers and clinicians in an interactive forum to discuss MND research.

University of Sydney

Members' Christmas Party
West Ryde

Information Evening for people recently diagnosed with MND Gladesville

11

Nov



Research into the diagnosis experience of MND

Researcher Sarah Remm from the University of Wollongong is currently looking for people diagnosed with MND to share their story about



their diagnosis experience. Your story will contribute to a study exploring diagnosis experiences of people with MND. If you live between Sydney, Illawarra and Goulburn, you are invited to participate in an interview, in a place convenient to you, where the researcher can discuss your experience of being diagnosed with MND. For more information contact Sarah Remm ph. 0408 814 019 or sarah.remm12@gmail.com. Or alternatively you can contact Professor Elizabeth Halcomb ehalcomb@uow.edu.au or phone 4221 3784. Recruitment to this study will close early October 2017. This research has been approved by the Human Research Ethics Committee, University of Wollongong (Approval no. HE16/056).

Research into understanding and acceptance of PEG tubes and noninvasive ventilation

Researchers from the School of Behavioural, Cognitive and Social Sciences at the University of New England are investigating the role of psychological flexibility on understanding and acceptance of PEG tubes and non-invasive ventilation (using a BiPAP machine) in people with MND. If you are aged 18 years or over and



have been diagnosed with MND/ALS (regardless of whether you have opted for one of these interventions), you are invited to participate in this study. Participation involves completing an <u>online survey</u> (smart phone and tablet friendly) that takes about 15-20 minutes. Click this link to go directly to the participation page. If you would like further information, contact James Pearlman at <u>jpearlm2@myune.edu.au</u>. This project has been approved by the Human Research Ethics Committee of the University of New England (Approval No. HE17-069, Valid to 03/05/2018).



Upcoming community fundraising events
Click to find out more.

Five Senses Twilight Market
Lambton Park



Charity Golf Day
Stonebridge Golf Club, Cessnock



23 Sep City Walk, Canberra



Navratri Garba 2017

Sep Bernie Millane Sports Complex, Kellyville



- 7 MND Awareness Trivia Night Cooma Ex-Services Club, Cooma
- Gundaroo Music Festival
 Gundaroo Park



The Illawarra Chilli, Spice and All Things
Nice Festival
Black Beach, Kiama



- Maria's Open Garden
 Wanniassa, ACT
- Craft Market Greystanes

 Greystanes



BINGO with BALLS - 7.30pm every Tuesday night at STONEWALL 175 Oxford Street, Darlinghurst. Charity donation to MND NSW.

Do you have a great idea for an event or activity that will raise funds for motor neurone disease care, support and research? http://www.mndnsw.asn.au/get-involved/fundraise.html



We appreciate your support

2017 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:

- Terry Memory, Arnies Table Tennis Club, for his continued support and recent donation of \$2,000.
- Mannering Park Public School who donated \$300 from their Mufti Day.
- Christopher Giorgioni who held a Fitness Session Fundraiser, raising \$1,260.
- The 'YOUBEAUTBOTTLERCORKER' Cup for donating \$1,800 from their golf day.
- Tim Allan who raised \$2,722 from his 'Tim's Big Shave' event.
- The Urunga Ladies Bowling Club for their support and donation of \$500.
- Henty Netball Club for donating \$1,800 from their Ladies Day.
- The University of Canberra Grizzlies Trivia Night which raised \$911.
- PhysioXtra in Erina for their continued support and recent donation of \$560.
- A donation of \$85 from National Seniors Australia from one of their monthly raffles.
- Aberdeen Ladies Golf Club for their donation of \$1,000 from their annual Tartan Charity Golf Day.
- The Sir Walter Scott Lodge 123 in Auburn who donated
 \$3,000 from their Ladies Charity Night Dinner.



Talk-Link MND Carer Wellbeing Program by telephone

Carers NSW and Motor Neurone Disease Association of NSW have partnered to offer the Talk-Link program to residents of NSW providing care to someone with MND. Talk-Link is a six-week telephone program for adult carers, facilitated by professional counsellors. There is no charge to register.



- Develop your coping and self-care strategies
- Learn from others caring for someone with MND
- Learn and implement healthy communication
- Learn about saying 'no' and feel okay about it

Time: 10am to 11am

When: Weekly – for 6 weeks commencing Tuesday 24 October 2017 Venue: Connect via any landline (free) or mobile telephone (mobile rates)

Who: For those caring for someone with MND in NSW

Register: ASAP (places limited so book early)

For more information or to register contact Carers NSW Carer Line ph. 1800 242 636

Manly Warringah Netball Charity Gala Day

Perfect weather and 112 teams entered made for a great day of netball and just over \$7,600 raised for MND NSW. A very big thank you to Monica Jacobs and the Manly Warringah Netball Association who organised the gala day which was also held for MND NSW in 2014. The day included lots of netball



games, merchandise sales, donations and a raffle of a large MND puppy. Thank you also to all the girls who played and to everyone who participated in the day.



Budding Entrepreneurs at Pittwater House School

Thank you and congratulations to the students involved in this wonderful project at Pittwater House School. What do you get when you bring together 14 students aged between 10-12 years of age to discuss business - the Pittwater House 'Little Entrepreneurs Club'. Over their lunchbreaks,

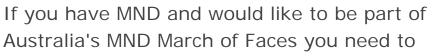


this savvy group formed a company called LEAFY and formulated their product - a series of brightly coloured wrist bands.

Before they launched, they identified their target audience, researched that audience's needs, created a product based on customer feedback and priced it according to demand and supply. Following several weeks of on-campus marketing, the 'Little Entrepreneurs' launched their wrist bands to the school community for \$3. The venture was so successful it raised \$640, which was donated to MND NSW. Pictured above are MND NSW CEO, Graham Opie (left), with Jarrad Dober, the teacher who hosted the 'Little Entrepreneurs Club'.

MND March of Faces Banners

MND March of Faces Banners are a photographic display of people with motor neurone disease. The MND NSW March of Faces banners are displayed at various MND awareness raising and remembrance events throughout the year.





provide a photograph of yourself and complete a consent form. You are welcome to include family in the photo if you wish. Family members are also able to submit a photograph in remembrance of a person who has died from MND. There is no charge to participate in this project and you can find out more information <u>here</u>.



Baden, Will and Cameron make a difference

In March 2014 Baden's grandmother Nicola was diagnosed with MND. After watching her slowly deteriorate and seeing first-hand how MND NSW assisted her in lending equipment, Baden and two of his school friends decided to hold a fundraiser at school. The fundraiser which raised \$1,000 was held in 2016 and



included a raffle and the sale of MND merchandise. The event also raised awareness about MND. Baden's grandmother Nicola passed away in August 2016. After the successful fundraiser, the boys were nominated for an award from the Independent Primary School Heads Association (IPSHA) and in July 2017 were given the opportunity to participate in the IPSHA Social Action Expo. For the Expo the boys prepared a presentation which told of Grandma Nicola's journey with MND. They spoke to teachers and children about how they organised their fundraiser, what challenges they had and, in the process, raised awareness of MND. The boys are pictured at the Expo from L to R -Will, Baden and Cameron. The day was a great success and an opportunity for the boys to collaborate and exchange ideas about successful fundraising campaigns with the view to sharing these ideas with their peers on return to school. It was an inspiring day and it taught the children that even at such a young age, they are capable of making positive changes to our world. Congratulations to Baden, Will and Cameron for their remarkable achievements.

Fundraiser in Woy Woy

Caroline Forrest organised a fundraiser at the Woy Woy Leagues Club which raised \$1,855 for MND NSW. It was a fantastic day for all who attended with raffles, bingo and entertainment. Thank you Caroline for your hard work!





Thank you Mischa and Elise

As part of their school project Mischa and Elise raised funds and awareness for MND with a raffle. Both of Mischa's grandfathers died from MND and Mischa is passionate about telling people about MND.

The girls are pictured with the first prize in their raffle - which raised \$835.70 -a limited release MND blue jug. Thank you Mischa and Elise!



Open Charity Dice Run

A big thank you to the Mid North Coast NSW Chapter Harley Owners Group who held an Open Charity Dice Run, a ride open to all makes and models of roadworthy bikes. The Dice Run in aid of MND NSW was a great success with 77 participants and \$2,618 raised! Well done to all.



Mental As Anything Fundraiser for MND

What a night! Mental As Anything at The Old Butter Factory in Telegraph Point, an event which raised \$2,000 and promoted awareness for MND.

A big thank you to Tracy Brown, Chontelle Shore and to everyone who worked so hard to make the night a success. Thanks



also to the generosity of the many local businesses who donated prizes and services.



Italian Dinner Dance

Thank you to the Regione Lazio Association who held an evening of dinner and dancing, and generously donated \$2,000 in support of MND. Our thanks also to Dianne Vogt who attended the evening on behalf of MND NSW. Dianne said of the night "It was a wonderful evening spent with lovely people."



Tathra Beach Women's Bowling Club

Thank you to Anne
Pearson and the Tathra
Beach Women's
Bowling Club who held
a very successful
Charity Day in June
with the proceeds to be
donated to MND NSW.



The photo (right) shows Anne's daughter, Louise Pearson, who has been living with MND for ten years, surrounded by bowlers from Tathra Beach, Merimbula, Tura Beach and Eden Bowling Clubs who took part in the event.

Red v Blue 2 Fight Night

Congratulations to Lisa Hancock who participated in the Red v Blue 2 Fight Night in Kincumber, and raised \$1,550 for MND NSW. To participate Lisa undertook 12 weeks of intensive boxing training and conditioning prior to the event. Although Lisa didn't win her match it was an amazing effort. Thank you Lisa!





Seeking Volunteers - Tamworth, Port Macquarie, Newcastle, Wagga Wagga, Canberra and Wollongong

Would you like to raise awareness of motor neurone disease in your community and help us fundraise?

Volunteers are essential to our organisation and highly valued members



of our team. We couldn't be the organisation we are without our volunteers. We rely on fundraising for a large portion of the dollars needed to provide the many services we have for our members.

We are currently looking for more Volunteers and Ambassadors in and around Tamworth, Port Macquarie, Newcastle, Wagga Wagga, Canberra and Wollongong.

Our volunteers help by selling merchandise, speaking at events to raise awareness, assisting at Community events and our Walks, organising raffles and selling raffle tickets and much, much more.

Be part of a fantastic community, raising awareness and helping others.

For more information contact Sarah ph. 8877 0999 or email sarahb@mndnsw.asn.au.

Seeking Ambassadors

Step up, speak out, raise awareness of motor neurone disease, and help others.

If you would like to make enquiries about our Volunteer Ambassador Program, whether you are considering becoming an Ambassador yourself or you would like one of our Ambassadors to speak at your event, contact Sarah ph. 8877 0999 or email sarahb@mndnsw.asn.au



Motor Neurone Disease Association of New South Wales

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

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

admin@mndnsw.asn.au

http://www.mndnsw.asn.au



f 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

MND NSW BOARD President Lara Kirchner Vice Presidents Alex Green, Roger Henshaw Secretary Anita Richter Treasurer Nick Shaw Board Members Phil Bower, Amy Critchley, Kirsten Harley and Ralph Warren

STAFF

Chief Executive Officer Graham Opie

Office Coordinator Petra Sammut

Admin and Receptionist Arja Aladjadjian

Accountant David Radford

Fundraising Manager Kym Nielsen

Fundraising Assistants Amanda O'Farrell Leah Phillis

Volunteer Coordinator Sarah Bouch

Support Service Manager Gina Svolos

Information Line Advisor Mary Clifton

Education and Carer Support Coordinators Kristina Dodds, Kate Maguire

FlexEquip Coordinator Maree Hibbert FlexEquip Assistants Youvanna Chantharasy, Nicole Smith FlexEquip Support Officer Julie Becke

Information Resources Coordinator Penny Waterson

MND Advisor

Team Leader Eileen O'Loghlen

MND Advisors

Madeleine Bowman, Chris Carroll, Sue Donaldson, Jo Fowler, Steven Harris, Michelle Malouf, Ana Petrovic, Susan Riggs

Coordination of Support Team Leader

Alexandra Matouk **Coordinators of Support** Anna Fisher, Jasminka Gojkovic, Samantha Potter, Marnie Roelink, Kim Sinclair, Kristie Stamford

> ...and many valued volunteers