



In this edition

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A Message from the CEO

With a lot of effort focused on the NDIS, some issues might appear to get pushed to the backburner. However, in regards to our advocacy efforts for people aged 65 years and over with MND, this couldn't be further from the truth. Level 3 and 4 Australian government My Aged Care (MAC) funding packages, for people aged 65 years and older, have been very hard to access and the levels of support currently available under MAC are grossly inadequate for a person with MND. We have been actively promoting the needs of people with MND in discussions with the Minister for Aged Care, Ken Wyatt, and senior bureaucrats. Advocacy can be a slow process but we are actively pursuing all avenues in this arena.

Please be aware that our holiday closing will be from 12 pm Friday 22 December 2017 until 9am Tuesday 2 January 2018. On behalf of the Board and staff of MND NSW I'd like to wish everyone a happy and safe Christmas and new year.

Graham Opie



Update from Support Service

It has been a busy end of year for the Support Service team at MND NSW with several events in Sydney and regional areas. It was great to see so many members and their families attend.

Our Members' Christmas Party on 25 November was very well attended with 80 adults and 24 children joining us for a fun afternoon. Santa visited, which all the children were excited about, as were a few of the adults.



MND Advisor Ana Petrovic with her daughter Masha at the Christmas Party

While not everyone celebrates Christmas, it is a time of year that reminds us of our family and friends and for some it can be a difficult time. For many it is a time to spend with family and friends. It can be a time to reflect on the past year, sharing memories including happy times, sad times, achievements, hopes and wishes. We hope this Christmas will be a time of peace and happiness for you and your loved ones.

In 2018 we will continue to conduct education programs and other events for members, families and service providers in Sydney and regional areas of NSW and the ACT. You can find out more about the events we are planning for 2018 on page 15 of this edition of *e-news*.

Gina Svolos, Manager, Support Service

Introducing new staff...

Yvonne Hamilton | Supporter Liaison Officer

I am delighted to have joined the MND NSW Fundraising Team as the new Supporter Liaison Officer specialising in Bequests and Major Gifts. I have spent 13 years raising funds in these areas. If you would like to have a confidential discussion about making a gift to MND NSW in your Will or a major contribution towards assisting our members, please contact me ph. 8877 0927 or yvonneh@mndnsw.asn.au



Our generous volunteers

Thank you to our volunteers who have been out and about:

- attending and speaking at dinners, events and functions to raise awareness of MND to those at the events
- manning merchandise stalls at markets and events
- organising raffles and selling raffle tickets
- assisting at support groups and information evenings
- organising and assisting at Walks to d'Feet MND

Thank you also to those who have:

- assisted with admin tasks at the MND NSW Centre at Gladesville
- packed the *News* ready for mailing out
- packed our fantastic Christmas cards ready for sale
- maintained and helped our garden to grow



2017 Crest Charity Golf Day

A huge thank you to Crest Air Conditioning in Bella Vista for the amazing total of \$25,000 raised at their recent Charity Golf Day. The day was a great success thanks to contributions from staff, suppliers, subcontractors and supporters.



The rain wasn't a show stopper for MND supporters at Walk to d'Feet MND Sydney

The results are in and we are very excited to announce that over \$68,500 was raised at the Sydney Walk to d'Feet MND held on 5 November at Blaxland Riverside Park. This is an amazing effort and a great way to finish off our Walks for the year. A special mention must go to 'Team Kiz' who raised over \$21,000 on their everyday hero page. For more photos and a video of the start visit our Facebook page <https://www.facebook.com/mndnsw>. Thank you to everyone who supported this event. We look forward to seeing you again next year.



MND Connect

MND Connect was held on 11 November at Sydney University. We were provided with great up-to-date information on MND research in Australia, with presentations from researchers who have been involved with MND for many years as well as those new to MND research. The program covered treatments and trials and care, and highlighted the significant steps forward made in these areas. As Dr Frederik Steyn said, "We may not have all the answers but we're a reminder; you're not alone. There's a research community who serve you". MND Connect was recorded and we will provide you with online viewing links when these become available.



Pudding time

Thanks to the amazing team at Pudding Lane, we are able to again offer our supporters the opportunity to purchase a Pudding Lane pudding at the very special price of \$34.95 with 100% of money raised from these sales supporting people living with MND. Stocks are limited at this price, so be quick and treat yourself to the best Christmas pudding around.



Maria's Open Garden

Thank you to Maria White for opening her beautiful garden in Canberra in support of her friend Margaret van Belkom. Maria opened her garden for three days in November and it was a huge success raising \$6,550. The event included a cafe, raffle, plant sale and Maria's cottage garden full of colour and life with several hundred flowers and plants.



10 questions to ask about residential aged care

Are you searching for a high quality residential aged care facility, reviewing the quality of your current residential aged care facility or deciding between two residential aged care facilities that appear similar? You may find the recently released '10 questions' series of leaflets produced in consultation with the NSW Aged Care Roundtable helpful. Each leaflet focuses on an individual aspect of care to increase consumer knowledge and make the journey into residential aged care easier: Contracts and fees, Staffing, GP services, Dental and oral health, Rural and remote care, Cultural needs, Aboriginal and Torres Strait Islander people, LGBTI(Q) needs, Facilities and lifestyle, Palliative care. You can get the leaflets free online at <http://www.10questions.org.au>



Remember if you have concerns about a residential aged care facility contact the Aged Care Complaints Commissioner ph. 1800 550 552 or email nsw@agedcarecomplaints.gov.au



Walk to d'Feet MND

Across NSW and ACT in 2018

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.

Illawarra 18 February 2018

Hunter March 2018

Forbes April 2018

Canberra June 2018

Penrith July 2018

Batemans Bay August 2018

Port Macquarie September 2018

Wagga Wagga October 2018

Sydney November 2018

More info when available at

www.mndnsw.asn.au/get-involved/walk-to-dfeet-mnd.html

New Walk Singlets

If you weren't able to make it to the Sydney Walk to d'Feet MND but would like one of these great new Walk singlets they can be purchased online. Get yours today. <https://www.online.mndnsw.asn.au/>



NDIS and MND NSW – Coordination of Support and FlexEquip

It has been a big year with the roll out of the NDIS for people under 65 years with new areas providing another bumpy start. We have learned a lot through this process and will continue to learn and adapt as the system develops and grows.



Our MND Advisors have contributed to this knowledge as they assist people to prepare for their NDIS planning meeting and our new pre-planning tool has proved to be very helpful to both the advisor and member in considering what you might need included in your plan. This is now available on our website at www.mndnsw.asn.au but we do encourage our members to contact their MND Advisor to assist them to prepare for their planning meeting. Don't hesitate to ring us for a copy to be sent and to discuss with your advisor.

MND NSW provides coordination of support for people who have NDIS plans living in Sydney, Central Coast, Newcastle and Illawarra areas. The coordinator of support is paid for through your NDIS plan to assist you to implement your plan and address any issues including negotiating your services with providers. It takes the stress off the member and their family to do this themselves and we encourage all people with MND who have a plan to access a coordinator of support. MND NSW Coordinators of support have expert knowledge about MND and can also liaise with your MND Advisor as needed.

Just a reminder that if you are having a planning meeting you need to talk to the NDIS representative about any assistive technology (aids and equipment) that you may have been provided by MND NSW FlexEquip service. The equipment needs to be included in your plan so that funds are available to rent these items if required. Some people question why we now charge those under 65 years for equipment. This is because we no longer receive any government support for this equipment as it is expected that service providers charge the NDIS for services. We provide all our services free of charge to our members. The cost is borne by the NDIS not the individual. We continue to

provide equipment free to our members who are 65 years or older as well and we hope that through our fundraising efforts either charitable or through rental fees paid for by the NDIS that we can continue to do this for many years to come.

Plenty of learning, laughter and knowledge gained

In early November, 18 carers of people with MND attended the MND NSW two day residential program for carers in Cowra. The aim of *Link and Learn* is to link MND carers so they can listen and support each other during the program and beyond, and learn more about MND, how to



support the one they are caring for and importantly, to take time out to care for themselves. Pat Duncan from Forbes joined us on day two to share her story on caring for her husband Stuart. Pat spoke about what worked well for them, what she might have done differently and the support she found helpful.

Over the two days we also had six local guest speakers who spoke on the practical aspects of caring. They all gave freely of their time to present relevant information on communication, swallowing and saliva; nutrition; preparing your home; breathing and MND; services available and living well as MND progresses. Time was also spent discussing the emotional aspects of caring, bringing the happiness back to your mind, body and spirit, and exploring why caring for the carer is so important.

At the end of each of our MND NSW education programs we ask participants to complete an evaluation. In the Link and Learn participant evaluation, all of the participants said that it was a valuable opportunity to meet with other people who know what it is like to be caring for someone with MND and the program met and exceeded their expectations. This year, we were very fortunate to have secured funding to run this program through a Westpac Community grant. The program was facilitated by Kristina Dodds, Education and Carer Support Program Coordinator, and Susan Riggs, MND Advisor for Western Sydney and Central West NSW.



28th International Symposium on ALS/MND - paper and poster abstracts now available free online

From 8 to 10 December 2017 the 28th International Symposium on ALS/MND will be held in Boston, USA. The annual Symposium is the largest medical and scientific conference specific to MND/ALS and is the premier event in the MND research calendar for discussion on the latest advances in research and clinical management. Over 1,000 delegates will come from across the world to listen to over 100 talks and see around 450 posters. To see what will be discussed in these presentations, you can now [download the full abstract book from the Taylor and Francis website](#) (volume 18, S2 November 2017).



Tirasemtiv not found effective for treatment of MND

The [MND Research Blog](#) reports that Cytokinetics Inc. has announced in their [official press release](#) published on 21 November 2017, that they will not be continuing work on tirasemtiv after disappointing results in the latest Phase 3 clinical trial. The trial, known under the acronym 'VITALITY-ALS', tested whether the drug has a beneficial effect on the breathing function and muscle strength of people with MND.



This is very unfortunate news for everyone affected by the disease, however, Cytokinetics are already testing another compound with the hope that this will be more effective and better tolerated than tirasemtiv.

Tirasemtiv is a drug that aims to improve quality of life of people living with MND by increasing strength of their skeletal muscles (controlling body motion and posture) and therefore postponing muscle fatigue. It compensates for the missing nerve signal from a motor neurone to a muscle that instructs it to contract. Tirasemtiv activates a protein called troponin by increasing its sensitivity to calcium, which is crucial for muscle contraction. [Read more on the MND Research Blog](#).

We appreciate your support

2017 has 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. Thanks also to the following supporters:

- The sixth annual Glen Sargood MND Fundraiser for donating \$2,000, thank you for your continued support.
- Brooke Elliot of Giving for Life Trivia Night for Charity raising \$6,549.
- Maimuru Public School for donating \$375 from their Farmers Market Fundraising Stall.
- The Lions Club of Frenchs Forest who donated \$1,779 from a Trivia Fundraising Night.
- Mary Edwards of Blue Illusion Northbridge for her continued support and recent donation of \$185.
- Champs, Cramps and Challenges for their donation of \$2,300.
- Mid Coast Connect who donated \$85 from a morning tea.
- The Wynyard Wobblers of Tumut for donating \$150 from their 50 year celebration as a footy team.
- Gundaroo Public School who raised \$371 from their Rock Star Dress up Day for MND.
- Cheryl Bobbin's Bargain Buyers Shopping Event raising \$243.
- A donation of \$267 from the Flinders Athletics Club.
- Sutherland Shire Netball Association who continued their support and donated \$460 from their 2017 season.

Networking Fundraiser for MND

Thank you to the Hub Advisory Group in Newcastle for this wonderful fundraiser, and for the donation from the event of \$1,556 to MND NSW. Special thanks to Shanelle Kidd from the Hub Advisory Group who coordinated the event.



FlexEquip equipment

FlexEquip is the rapid response equipment service of the Motor Neurone Disease Association of NSW that provides equipment for adults of any age diagnosed with MND in NSW and the ACT.



FlexEquip provides equipment after referral from your allied health professional. This is usually your occupational therapist, speech pathologist or physiotherapist. A referral is required to ensure the item of equipment is suitable for you to use in your home environment. If specialised or individualised equipment is required, FlexEquip can provide a standard version of the item while the more individualised item is sourced through another service by your health professional. This is because individualised items are, by their design, useful for the individual and difficult to re-issue.

Equipment in past 12 months

THANK YOU, to all who have helped MND NSW fundraise this year. This enabled FlexEquip to purchase 141 new items of equipment for FlexEquip at a cost of \$189,233. Some of the items purchased included 25 electric raiser recliner armchairs, 25 slings, 20 bathroom aids and 7 power wheelchairs, including 5 tilt models. In the past 12 months FlexEquip provided over 1700 equipment items to 308 members throughout NSW and the ACT. Additionally, for members in regional areas where it is too expensive for FlexEquip to arrange delivery of our own beds, we paid for the hire of about nine beds per month. We also retrieved 1,795 items and prepared them for reissue.

Christmas New Year close

MND NSW, including FlexEquip, will be closed over the Christmas and New Year period from 12pm Friday 22 December 2017, reopening Tuesday 2 January 2018. If there is an emergency breakdown of FlexEquip equipment during the MND NSW Christmas close period please contact your occupational therapist or speech pathologist to assist you in arranging a repair or, if they are not available, contact your local hospital. If there is a risk to your health go to your nearest

hospital. Please also let FlexEquip know as well so we can follow up when we reopen. FlexEquip can be contacted on 02 8877 0999.

Remember if you are using battery operated equipment every day - such as a power wheelchair, hoist or communication device - then the battery needs to be charged overnight.

The FlexEquip team: Julie, Nicole, Youvanna and myself would like to wish everyone a very safe and very happy memorable holiday.

Maree Hibbert, FlexEquip Coordinator

Submissions open for 2018 MND March of Faces Banner

Australia's MND March of Faces Banners are a photographic display of people with motor neurone disease. The banners are displayed at various MND awareness raising and remembrance events throughout the year. Our 20th banner in the MND March of Faces series will be displayed during MND Week 2018. If you have MND and would like to be included in the new banner, you need to complete a permission form and submit a photograph of yourself. Family members are also able to submit a photograph in remembrance of a person who has died from MND. [More info here.](#)



Darby Falls Rose and Flower Show

The lovely community of Darby Falls have this year supported MND NSW with their annual Darby Falls Rose and Flower Show. Thank you to Thora Tarrant and everyone in the community for their support. A generous \$800 was donated. Our thanks also to Raylene McLaughlin who attended on behalf of MND NSW. Pictured is Thora (left) and Raylene on the day.



THE CORRILEE FOUNDATION

bringing charities and people together

22ND CELEBRITY CHARITY TENNIS EVENT 2018

IN MEMORY OF PETER DOOHAN
RAISING MONEY AND AWARENESS FOR MND NSW



PHIL DENT



JOHN ALEXANDER

Our 22nd Tennis Day will be honouring two of Australia's Davis Cup Players, Doubles Partners, great champions of the game and great mates John Alexander MP and Phil Dent

JA & Phil will also be interviewed by Alan Jones

Join us for a great morning of competitive (but friendly) tennis at Manly Lawn Tennis Club
Round Robin Tennis with the Champions

You will be playing a "timed round robin" consisting of 5 rounds of mixed doubles, rotating with 24 other players including former professional players and celebrities players which include:
Mark Edmondson + Bob Giltinan + Kim Warwick + Lesley Bowrey + Glenn Knox
+ Michael Tabbutt + JA + Phil Dent + Anton Enus



MC DEBBIE SPILLANE

DATE - Sunday 14th of January 2018

WHERE - Manly Lawn Tennis Club
27 Belgrave St Manly NSW 2095
(02) 9977 6023

WHEN - 9:15 am Welcome - please be on time.

9:30 am Match Play begins, a light morning tea will be served at 11:00am
12:30 Match play ends.

12:45pm for 1:00pm Lunch & drinks for players and guests in the Manly Lawn Club House.

COST - \$300 per player (includes, Tennis morning tea, lunch, drinks and players prizes)

\$100 for non-playing lunch guests (includes drinks)

Presentation, Interviews, Raffle prizes and Auction items.

RSVP - Tanya Lee.

Mobile: 0418 222 513

Email: tanya@corrileefoundation.org

Note - RSVP No later than Monday 8th January 2018.

SPONSORS



Do you have a great idea for an event or activity that will raise funds for motor neurone disease care, support and research?

See here for how you can get started.

MND NSW Support Service events for 2018

Are you newly diagnosed with motor neurone disease? Caring for someone with MND? Would you like to ask an expert panel your questions about MND?

MND NSW conducts regular education and information sessions for people living with motor neurone disease, family members, carers and friends. MND education and information sessions are held throughout the year in Sydney and other areas of New South Wales and the Australian Capital Territory. There is usually no charge to attend an MND NSW education or information session if you are a person living with motor neurone disease, a family member, carer or friend. However, bookings are essential.

Keep an eye on www.mndnsw.asn.au and future *e-news* editions for 2018 dates and locations for following events.

Information Evening for people recently diagnosed with MND, their family and friends

Information evenings for people who are newly diagnosed with MND ensure that help is available at a time when many questions need to be answered. Information Evenings are held every two months at the MND NSW Centre at Gladesville. Upcoming dates - 5 December 2017, 13 February 2018, 17 April 2018.



Living well with MND Day

Living Well with MND is a one-day program providing a range of strategies to live well with MND and to maintain independence for people with MND, their family and friends. It also provides the opportunity for you to have your questions answered by a range of health professionals with expertise in MND, and to meet others who understand what it is like to live with MND.



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Care for Carers

For the carer (usually a family member or friend) of a person with motor neurone disease, the Care for Carers program is a four-day program, held one day a week for four weeks. It explores the physical and emotional aspects of caring so you are better able to look after a person with MND at home, while still taking care of yourself.



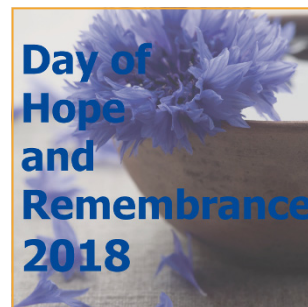
Ask the Experts

Do you have questions about current therapies or research into MND? What palliative care can offer people living with MND? Are more people being diagnosed with MND? Bring your questions to the annual Ask the Experts forum.



Day of Hope and Remembrance

Our annual Day of Hope and Remembrance is a special occasion for all those whose lives have been touched by MND, including people living with MND, family, friends, supporters, volunteers and those working with MND. This afternoon of hope and remembrance marks the beginning of MND Awareness Week and is usually held in May.



Support groups and coffee mornings

MND support groups and coffee mornings provide the opportunity for people living with MND to meet together regularly in their local area. Guest speakers include health workers who know about MND or a person with expertise in a topic that may be of interest to the people at the meeting.



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Past carers lunch

Held several times a year in various locations in NSW and the ACT, the past carers lunch is a get together for people who have experienced bereavement during the last year. It provides an opportunity for you to reconnect with old friends from MND NSW and to meet others who have cared for someone with MND. After lunch there will be a talk and discussion about some of the experiences of bereavement and possible ways to manage these.



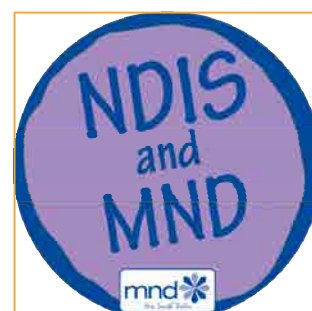
MND Aware for health and community care professionals

The MND Aware face-to-face training sessions are conducted to support health and community care professionals make a real difference to a person with MND, their carer and family. At these sessions participants learn about the impact of MND and effective ways of responding to people with MND.



Supporting NDIS Participants Living with MND for health and community care professionals

This program is for health and community care professionals who provide support services to enable people to remain at home and may have the capacity to support NDIS participants with MND and would like to find out more.



Keep an eye on www.mndnsw.asn.au and future e-news editions for 2018 dates and locations.



www.online.mndnsw.asn.au

The Cavalcade of History and Fashion

Thank you to the Lions Club of Canberra Brindabella who held a wonderful afternoon fashion parade in support of MND, raising \$6,500.

The Cavalcade of History and Fashion

is a collection of original historic gowns and accessories dating from the 1700s preserving Australia's social and fashion history. Our thanks also to MND NSW Ambassador Nicole Papasidero for attending the event. Nicole is pictured (far left) accepting the donation cheque from June Ceretti of the Lions Club of Canberra Brindabella.



10th Annual Spring Art for Charity

Thank you to the Queanbeyan Arts Society who held their 10th Annual Spring Art for Charity in Canberra supporting MND. It was their most successful annual art show with many wonderful artworks on display.

A donation of \$4,486 was made to MND NSW, and we thank all members of the Society for their very generous support. Pictured above (L-R) Amy Critchley (MND NSW Board Member), Gordon Ramsay (Minister for the Arts ACT MLA), Barry Cranston (President, Queanbeyan Art Society) and Tim Overall (Queanbeyan Palerang Mayor).



LJ Hooker Cessnock Charity Golf Day

A big thank you for the generous support from LJ Hooker Cessnock who held a Charity Golf Day which raised \$4,001 for MND NSW.



Please help us continue to help people affected by MND

Earlier this year I was at the Riddla MND Golf Fundraiser, an annual local event organised by Ann Ridd, raising funds for MND NSW. As I listened to Ann's opening speech I was struck by the incredibly powerful impact of a community event - not only raising vital funds but the supportive community created around the event. Here is an excerpt from Ann's speech. Through your support we can continue to make an impact in the lives of our members.



Kym Nielsen, Fundraising Manager, MND NSW

Community impact

"Welcome to our 6th Riddla MND Golf Fundraiser! I want to thank each and every one of you here today for your ongoing support of our fundraiser, which of course, is not only to have a great day but to raise much needed funds for the Motor Neurone Disease Association of NSW.

But today is not just about having a great day with your mates, it's an opportunity to raise awareness of MND and funds for MND NSW. Nearly all of us here (have) heard of MND, but never understood what it was about. I know I was one of those people. But when our son, Nathan, was diagnosed in late 2011, we quickly learnt what this horrible disease was all about. In short there is no cure, no medication to slow the disease and frustratingly absolutely nothing we can do.

I was trying to find a way to share with you how this debilitating disease affects sufferers. I thought the best way was to read to you a class project that was given to Nathan's daughter, Casey. They had to write a speech about something people may not know. This is an excerpt...

Good morning 5/6W & Mrs Attard. Today I am going to be informing you about a rare disease called Motor Neurone Disease. It has no cure and not many people I know have it but

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the ones that do have MND I feel sorry for. MND isn't caused by anything like smoking, not eating healthy or drinking too much alcohol. It just comes and it's nobody's fault. I know a lot about MND because sadly my dad has been diagnosed with it and I know how much he struggles. MND isn't a disease that affects old non-fit and unhealthy people, it actually affects most young, fit healthy people, where they can't speak properly, their muscles shut down completely and eventually they have to use a wheelchair. My dad was out surfing one day when he first got diagnosed with MND; suddenly he couldn't paddle because the MND had got to the muscles in his arms and also his speech. Later on it spread into his legs and soon he needed a wheelchair. You may be wondering but what does he do all day and the answers to that are eat, drink, sleep and use the computer. He can still move his head and that's about it, he has a special dot sticker on his forehead that has a camera inside that works like a mouse for the computer. Thanks to fundraising like the ice bucket challenge we have raised enough money to find a very important gene that causes MND. People who have MND normally only live up to two and half years but my dad is staying strong trying to fight this rather nasty disease and has lived more than double what he was supposed to. Thank you 5/6W for listening to my speech and I hope you have learnt a lot about MND. Thank you.

MND NSW assists people with MND live life to the fullest, enabling members to remain living at home; they also subsidise ongoing cost of non-invasive ventilation so the task of breathing is easier. Computer access devices allow people to stay connected when speech and arm movements are hard. Many of you would have seen how wonderful the app on Nathan's computer lets him converse with us all and keep in touch with social media. They help make every moment count. This is why we are here today - to help them keep up their great and vital work. Thank you!" Ann Ridd.



Motor Neurone Disease Association of New South Wales

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

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

admin@mndnsw.asn.au

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

 <http://fb.me/mndnsw>

ABN 12 387 503 221

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Team Leader

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Coordinators of Support

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**...and many valued
volunteers**