



In this edition

Get in quickly - Walk to d'Feet MND Sydney on Sunday 3 November... MND research grants 2020 announced... On the road to Ballina in November... Terrific Young Walk to d'Feet MND... Christmas Orders - support our fundraising efforts... March for MND Larapinta Adventure 2020... and more.

A Message from the CEO

Why not grab your family, friends and dogs and head to Sydney Park this Sunday 3 November for our last Walk to d'Feet for 2019? It's a new and exciting venue this year. 2019 has been an amazing year for Walk participation, over 2500 people have travelled to events across NSW and the ACT to raise over \$275,000 for support, education, equipment and research. Help us crack 3000 participants and the \$300,000!

Other upcoming events include education and carer programs in the Hunter and Ballina. There is also the MND Connect event in Perth in December that will be live streamed.

Thanks to your donations MND NSW has once again contributed a significant amount to research. The 2020 MND research grants have been allocated with over \$2.9 million going to support the best MND research. A full list of grants can be found on page 8.

Our AGM took place in late October. For a full list of Board members please go to the back page.

See you at the Walk on Sunday.

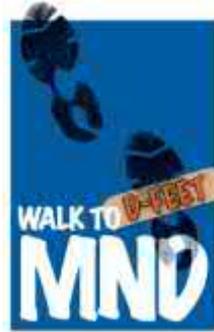
Graham Opie



Walk to d'Feet MND Sydney, 3 November

Sydney Walk to d'Feet MND is on this weekend, Sunday 3 November, at Sydney Park at St Peters. You can register on the day, so don't miss out.

We'd love you to get your family, friends and of course, your pooch together and come along so we can show support for people battling the challenges of MND. All funds raised will go toward providing essential equipment, services, support and research for people living with MND and their loved ones. Find out more.



New Merchandise

They're back in stock just in time for Summer. Order your 'Never give up' tights and why not team them with one of our trendy new visors? Get your order in today.



Upcoming Support Service Events

Click the event for more information or contact the MND Info Line ph. 8877 0999 or Freecall 1800 777 175 or email reg@mndnsw.asn.au.

7-8
Nov Link and Learn
Hunter

11
Nov Information Evening for people diagnosed with MND
Ballina

11
Nov MND Hope and Remembrance
Ballina

12
Nov MND Carers Morning Tea
Ballina

MND Connect

2 December - Perth or live stream

Leading international ALS/MND researchers are providing the MND community with the opportunity to ask questions about the latest research advances at the 2019 MND Connect - on 2 December in Perth. If you can't attend, register for the live stream. [Find out more.](#)



Never Give Up Raffle Winner

Congratulations to Deidre Kornacki who has won the Never Give Up raffle! Deidre has won a prize voucher for a three night stay for a family of five in a holiday villa at the Big4 Easts Beach Holiday Park, Kiama.

[Join us on the March for MND to provide the best possible support for people living with motor neurone disease, their family and carers](#)

We're heading to the heart of Australia to trek the legendary Larapinta Trail and we're calling on people who are passionate about hiking to get involved.



On this incredible adventure, you'll trek through the Australian outback on one of the

most spectacular walking trails. Regarded as one of Australia's premier walking tracks, the Larapinta Trail winds from the old Alice Springs Telegraph Station toward the peak of Mount Sonder. To top it off, you'll also be raising funds for MND NSW to provide essential services and support for people living with motor neurone disease. [Register your interest today.](#)

Link and Learn registrations now full

Registration for our upcoming '[Link and Learn](#)' two-day residential program for carers on 7 and 8 November is at capacity and has now closed. We are looking forward to meeting the participants and providing them with the opportunity to hear from a range of health professionals and MND NSW staff with expertise in MND, in a relaxed and informal setting.



Living Well with MND Information Days

We held our Living Well with MND Information days in Berry in September and Ryde in October. In an endeavour to make our Living Well with MND days more accessible to those unable to attend we trialled videoing the speakers from the Living Well with MND Ryde event. We'll keep you posted!



Ballina

We are off to Ballina in November. For more information on the events listed below and to RSVP contact reg@mndnsw.asn.au or ph. 8877 0999 or Freecall 1800 777 175. Please let us know if you have any special mobility or dietary needs.

There is no charge for you to attend but you will need to reserve your place.

MND Hope and Remembrance - Ballina 12pm-3pm, 11 November

We welcome you, your family and friends to join us in a gathering to honour and celebrate those who have lost their lives to MND. Following a brief ceremony there will be a light luncheon and opportunity to chat and connect with others. [Find out more.](#)

Information Evening for people diagnosed with MND - Ballina 6pm-8pm, 11 November

If you or someone close to you has been diagnosed with MND, this evening will provide an opportunity to have some of your questions answered in an informal setting. You will also be able to meet others who also understand the impact of living with MND. [Find out more.](#)



MND Carers Morning Tea - Ballina 10.30am-12.30pm, 12 November

Are you caring for someone who has MND? Join us for a complimentary morning tea which offers an opportunity for you to meet others caring for someone with MND. [Find out more.](#)



Together We Can 2019 Walk to d'Feet MND

Thank you to our supporters
Walk to d'Feet MND Young
20 October 2019



What an amazing turn out to the first Walk to d'Feet ever held in Young. We had 272 participants who got involved and helped us to raise \$20,352 to date! To put this in perspective, this money could buy an electric wheelchair, four shower chairs and four transfer belts and make a real difference to people living with MND.

We would like to acknowledge the support of the amazing local businesses who helped us make it such a special day including; Jaclyn from That Coffee, The Lions Club of Young, Chloe from Clicky Cookies, Molly from Moava, Bev Moloney and her wonderful preserves stall, our face painter Katie, Toni from Salami Bros Pizza, Stephen from Whip 1 4U Ice Cream Van and Sheree from the Criterion Hotel.

The support we've had from the community is inspiring. We can't thank everyone who got involved enough for making the walk so successful and bringing along family and friends (and of course pooches) to show support for people living with MND and their loved ones. Together, we've made a real difference in the lives of people touched by MND.

Supported by



Community Calendar

Click the event for more information.

2
Nov Harrington Expo
Harrington

4
Nov High Tea
Whites Meadow

29
Nov Dave Matthews Seniors Tennis Tournament
Nelson Bay Tennis Club

3
Dec MND Christmas Wrapping Stall
Deepwater Plaza Woy Woy

27
Dec Market Stall
Kevin Sobels Wines Pokolbin

9 May
2020 Beat the Beast Team Roping Spectacular
Attunga Sport and Rec Grounds

7 Sep
2020 March for MND - Larapinta 2020

Do you have a great idea for an event or activity
that will raise funds for
MND support and research during 2020?

MND NSW supporters who organise events and activities
that raise funds for motor neurone disease provide much
needed funds for MND care, support and research.

In the past supporters have organised golf days,
trivia nights, bowls afternoons, auctions,
afternoon teas, balls, stalls, treks and walkathons.

Help us provide much needed services
for people living with MND with your event.

<http://www.mndnsw.asn.au/get-involved/fundraise>

MND research grants 2020

The MND Research Institute of Australia (MNDRIA) has awarded almost \$2.9 million to support the best MND research commencing in 2020. MNDRIA is indebted to the generosity of donors and the State MND Associations, including MND NSW, who fund this research.



The suite of grants awarded at the annual grants allocation meeting on 11 October 2019 comprises the Betty Laidlaw MND Research Prize for a mid-career researcher, two postdoctoral fellowships and 20 innovator grants.

Betty Laidlaw MND Research Prize Dr Shyuan Ngo University of Queensland, QLD

From the nucleus to the powerhouse: investigating how TDP-43-mitochondrial interactions wreak havoc in MND

In MND, the TDP-43 protein forms clumps inside neurons. While we know that these clumps of TDP-43 are toxic to the cell, we don't know how this leads to neuronal death. We will use neurons made from human skin cells to study whether interactions between TDP-43 and mitochondria (the powerhouse of the cell) causes a breakdown in the mitochondrial network, and an inability of mitochondria to function properly, ultimately leading to the death of neurons. This will allow us to identify a key cause for the death of neurons in MND; a critical step towards developing treatments.

Bill Gole MND Postdoctoral Fellowship (2020 – 2022) Dr Luke McAlary University of Wollongong, NSW

Targeting Prion-Like Strains of TDP-43

Toxic proteins in MND are capable of spreading from cell to cell in the spinal cord and brain by recruiting normal healthy protein. This spread is controlled by the shape of the toxic protein, some shapes spread more readily than others. Advanced imaging technologies have been produced where we can see the shape of individual proteins. We plan to use these imaging technologies to define the shape(s) of toxic MND proteins and apply a broad set of drug discovery methods to identify the best drugs to target them.

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Beryl Bayley MND Postdoctoral Fellowship (2020 – 2022)

Dr Mehdi van den Bos

Westmead Hospital, NSW

Deep learning as a tool to advance the diagnosis and pathophysiological understanding of ALS

ALS can be a difficult disease to diagnose and is proving even more challenging to cure. Increasingly we are realising that early intervention is needed and there are many signs brain overactivity is an early driving cause of the disease. This fellowship proposes to use advanced neurophysiological methods (probing brain function with magnetic brain stimulation and brain wave recordings) together with artificial intelligence (the technique of deep learning) to make possible early diagnosis, improve our understanding of the drivers of the disease in patients and find a reliable biological marker to accelerate drug trials that will deliver a cure.

Charcot Grant

Associate Professor Bradley Turner

Florey Institute of Neuroscience and Mental Health, VIC

Development of a novel splice-switching molecular therapy for MND Mutations in the SOD1 gene are a common cause of MND. We have developed a novel therapy using powerful genetic designer drugs which target and 'turn off' the offending SOD1 gene. In this project, we will comprehensively test our therapeutic approach in motor neurons grown from MND patients and in MND mice. We predict our therapy will significantly slow down disease and protect motor neurons in MND mice due to suppression of the SOD1 gene. This will provide crucial support for continued development of our genetic therapy approach for MND.

Peter Stearne Familial MND Research Grant

Professor Julie Atkin

Macquarie University, NSW

Novel mechanisms of neurodegeneration induced by dysfunctional actin dynamics in MND

Actin is the most abundant protein in humans. It has many important functions, including forming the synapses that enable nerve cells to talk to each other to co-ordinate movement and brain activities. To perform these functions, actin continuously assembles and

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disassembles to form long filaments. Abnormalities in actin are known to be present in Alzheimer's and Parkinson's disease but it is unknown if they exist in MND. However we have obtained exciting new evidence that actin is also abnormal in MND. This project will examine how this occurs and whether already available drugs that regulate actin are protective in MND.

Jenny Simko MND Research Grant

Dr Samantha Barton

Florey Institute of Neuroscience and Mental Health, VIC

Could abnormal myelin composition be exacerbating neuronal dysfunction in MND?

Oligodendrocytes (a type of glial cell that forms myelin) have two key roles essential for motor neuron function: to myelinate (coat) neurons and to provide sources of energy to neurons. In MND, both functions are impaired but the contribution to neuronal dysfunction remains unknown. We will comprehensively assess oligodendrocyte function in post-mortem tissue and then interrogate mechanisms of dysfunction using a highly innovative stem cell model whereby we take MND patient stem cells and turn them into mini-brain structures in the lab. Identifying the cause of altered myelination and energy production will address a gap in current knowledge and highlight the relevance of oligodendrocytes when searching for effective therapies.

Mavis Gallienne and Graham Lang MND Victoria Research Grant

Professor David Berlowitz

Austin Health/University of Melbourne, VIC

NIV@Home

Approximately 80 people with MND start non-invasive ventilation (NIV) annually in Victoria. NIV is currently established with a same-day hospital admission and then another overnight stay within two months. These admissions are burdensome and time consuming for patients, their families and carers. An ever increasing demand for inpatient beds can also delay access to NIV further increasing burden and anxiety. Once on NIV, trouble-shooting involves hospital attendance or a home visit from Outreach nursing. NIV@Home will pilot whether substituting inpatient admissions and sleep studies with home implementation and telehealth results in equivalent NIV usage but a better patient experience.

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Col Bambrick MND Research Grant

Dr Richard Gordon

University of Queensland, QLD

Targeting inflammasome-driven neuropathology and motor neuron death in MND using a clinically approved cancer drug

Chronic activation of the immune system and persistent inflammation in Motor Neuron Disease (MND) are considered to be key drivers of motor neuron loss. Breaking this cycle of inflammation and motor neuron death is currently considered one of the most promising treatment approaches for MND. In this study, we will test a promising FDA-approved drug which we believe can block both inflammation and death of motor neurons in MND. Most importantly, since this drug is already approved for human use, it can directly progress into clinical trials for MND if the outcomes of our research are positive.

MNDRIA Innovator Grant

Dr Albert Lee

Macquarie University, NSW

Clearance of TDP-43 by PROteolysis Targeting Chimera (PROTAC) dual targeting to treat amyotrophic lateral sclerosis (ALS)

The pathological feature of MND is the presence of protein inclusions inside motor neurons – comprising mostly of the protein TDP-43. TDP-43 inclusions are a major contributor to disease, and therefore we are investigate ways to prevent formation and clearance of these TDP-43 inclusions. We have identified a protein that binds TDP-43 in motor neurons, and we will use this information to construct a therapeutic intervention that combines this with a new technology called PROteolysis TArgeting Chimera (PROTAC). We will perform pre-clinical evaluation of our PROTAC to specifically target and clear TDP-43 from neurons, to restore normal cellular function and health.

MNDRIA Innovator Grant

Dr John Lee

University of Queensland, QLD

Investigating the therapeutic inhibition of CXCR2 as a disease modifying treatment for motor neurone disease

Increased activity of our immune system can contribute to MND. One component that is gaining momentum as key driver of neuron death is CXCR2. CXCR2 is known to recruit our immune cells to site of

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injury. We believe that unwanted activity of CXCR2 is contributing to MND progression. This study will use a drug that will block CXCR2 in mouse models of MND, and in MND patient samples, to understand if this drug can dampen immune response and protect motor neurons. This will help determine whether targeting CXCR2 may be a viable therapeutic option to benefit people with MND.

Superball XI MND Research Grant

Dr Susan Mathers

Calvary Health Care Bethlehem/Monash University, VIC

Identifying and responding to the health literacy needs of people living with MND/ALS – a coordinated national approach

This project aims to understand how easy or difficult it is for people with Motor Neurone Disease (MND) to find, understand and make use of information about managing their life with the disorder. Specifically, what help do these people, together with their families or carers, need to make the decisions which are best for them? It also intends to explore how people living with MND interact with those providing information and advice on their care. Lastly the project aims to develop innovative ways of providing information and delivering health care that consumers of health services find useful and that support decision-making.

MNDRIA Innovator Grant

Professor Pamela McCombe

University of Queensland, QLD

Possible gut derived toxins in ALS: prevalence and effects on outcome
Some of the risk of ALS is genetic and the remainder is non-genetic (environmental). In this study we will look for circulating neurotoxins in the blood of patients with ALS. This is based on preliminary studies that have already shown that some patients have elevated levels of formaldehyde and D-serine. This is significant because the source of these toxic molecules could be the gut microbiota. Some microbes, such as the Archaea could produce these toxins. This could provide a possible explanation for how gut dysbiosis could contribute to disease and provide opportunities for treatment.

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[MNDRIA Innovator Grant](#)

[Dr Fiona McKay](#)

[University of Sydney, NSW](#)

Natural Killer cells in amyotrophic lateral sclerosis

The immune system is intimately involved in the disease process in MND and influences the rate of disease progression. This project examines a potent immune cell type called the “natural killer cell” in MND. Natural killer cells are increased in the blood in MND and found in the spinal cord in the mouse model of disease but their role in MND is unknown. We will characterise NK cells in MND patients and their relationship with disease and the inflammatory process, as well as the effects of an antiinflammatory therapy, dimethyl fumarate, on NK cells in MND.

[MonSTaR MND Research Grant](#)

[Dr Marco Morsch](#)

[Macquarie University, NSW](#)

The unexplored posttranslational modification (SUMOylation) of TDP43 affects aggregate formation and localisation

Aggregation of the protein called TDP-43 is a hallmark feature of ALS. The movement of TDP-43 out of the nucleus appears to be detrimental for neuron survival. For TDP-43 to localise into the right compartment, it undergoes post-translational modifications (PTMs). We recently found for the first time that one of these PTM-pathways (SUMOylation) is critical for the localisation of TDP-43 aggregates, nerve growth and cell-viability. In this proposal we aim to assess the implications of SUMOylation in vivo and in patient tissue. Importantly, the SUMOylation pathway has been recently demonstrated to be a promising therapeutic target in other neurodegenerative diseases.

[Benalla Act to d'feet MND Research Grant](#)

[Associate Professor Lezanne Ooi](#)

[University of Wollongong, NSW](#)

Targeting cortical hyperexcitability and neurodegeneration in amyotrophic lateral sclerosis

The processes that control how motor neurons communicate with one another are affected even before symptom onset in ALS. Since these changes in electrical properties are common to familial and sporadic ALS, these mechanisms are likely important in disease onset and

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progression. We have identified how and why these electrical properties of motor neurons change and now we will test whether preventing these changes, using pharmacological and genetic approaches, can protect motor neurons from degeneration.

MNDRIA Innovator Grant

Dr Mary-Louise Rogers

Flinders University of South Australia, SA

Urinary Neopterin as a candidate biomarker that can be used to test disease progress in clinical trials for Motor Neurone Disease

We have identified a protein in urine of people with MND called p75ECD that can track progress of the disease. This was a significant break-through, with our laboratory being world leaders in urinary MND biomarkers. We will now examine an additional novel urinary biomarker called Neopterin, which is known to be influenced by immune status. We will determine if urinary neopterin levels in MND patients are different to healthy people useful for clinical trials to measure disease progress. Neopterin will also be compared to urinary p75ECD. The development of urinary biomarkers is critical to success of finding useful MND therapies.

Fat Rabbit MND Research Grant

Dr Frederik Steyn

University of Queensland, QLD

Tipping the Scales on MND: Preclinical validation of a polypharmacological treatment to slow disease progression

MND is a complex and heterogenous disease, and so to treat MND, drug candidates must target multiple components of disease. We have identified ghrelin (a gastrointestinal peptide hormone) as a possible target for treatment. Ghrelin has multiple biological effects that could slow disease progression, and treatment of MND mice with ghrelin results in a dramatic extension of survival. However, ghrelin is unstable and clinical use of ghrelin is thus unlikely. We will test a stable compound with biological actions similar to ghrelin. It is expected that this drug will act via multiple mechanisms to slow disease progression and extend survival in mice with MND.

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MonSTaR MND Research Grant

Dr Sicong Tu

University of Sydney, NSW

Utilising multi-modal connectivity and artificial intelligence to track disease progression in ALS/MND

The absence of objective clinical markers for monitoring and predicting disease progression is a significant barrier undermining clinical care and successful clinical trial outcomes in ALS/MND. Multi-modal brain connectivity and artificial intelligence modelling are two cutting-edge techniques at the forefront of neuroscience research. This project seeks to develop these techniques in ALS/MND to advance our understanding of disease progression and develop robust and objective clinical tools for monitoring and predicting disease trajectory to improve clinical care and provide sensitive outcome measures for future therapeutic trials.

Run MND NSW Research Grant

Dr Kara Vine

University of Wollongong, NSW

Non-invasive drug delivery across the blood brain barrier: Improving the bioavailability of drugs for MND

A problem treating Motor Neurone Disease is the blood–brain barrier (BBB). The BBB prevents the passage of certain drugs from the blood into the brain. We have designed a drug carrier that can increase the delivery of drugs into the brains of mice with MND. We will enhance this delivery further using focused ultrasound to temporarily and safely disrupt the BBB, thereby increasing drug delivery into the brain. This project will be the first validation in rodents of an ultrasound-mediated delivery strategy for MND and will allow for the immediate scale up and further testing of our novel approach.

MNDRIA Innovator Grant

Dr Adam Walker

University of Queensland, QLD

New mouse models of TDP-43 pathology

Most people with MND develop pathology in neurons that contains the protein TDP-43. This protein undergoes many biochemical alterations, but how this relates to disease remains unclear. This project will use newly developed virus technology to produce several different

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pathology-associated variants of TDP-43 in mice. This will allow us to create new mouse models that will be useful for both investigating disease mechanisms as well as testing treatments for MND.

[NTI MND Research Grant](#)

[Associate Professor Anthony White](#)

[QIMR Berghofer Medical Research Institute, QLD](#)

Boosting microglia phagocytosis as a therapeutic approach to treat MND

Abnormal immune function in the brain has an important role in MND, but the development of new drugs to target this process has been hampered by a lack of effective model systems in which to test drugs. We have developed a new platform using human microglia (the resident immune cell of the brain) grown from blood cells of people with MND. In this project, we will use this platform to screen new and repurposed drugs for their ability to promote normal function of microglia in MND. This will greatly improve the likelihood of new drug treatments for people with MND.

[Robert Turnbull MND Research Grant](#)

[Dr Kelly Williams](#)

[Macquarie University, NSW](#)

Comprehensive transcriptome analysis of neuroanatomical regions with variable pTDP-43 pathology in sporadic ALS patients

Sporadic ALS cases show a hallmark pathology in the central nervous system (CNS), however the quantity and location of this pathology can vary greatly amongst cases. We aim to investigate differences in gene expression in various regions of the CNS to understand the biological mechanisms that underly this variable pathology and why some CNS regions may be 'protected' from developing the pathology. We also aim to determine whether the gene expression changes are also present in patient blood samples, with the potential to be used as a disease biomarker.

[MNDRIA Innovator Grant](#)

[Associate Professor Trent Woodruff](#)

[University of Queensland, QLD](#)

Transcriptomic and Functional Evaluation of Immune-Activated Monocytes in MND

The immune system is now recognised to be different in MND.

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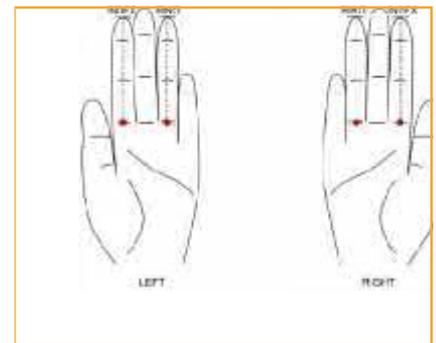
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Alterations in both protective immune cells, as well as 'disease-driving' immune cells, can accelerate MND progression. Our research has identified an immune cell (called monocytes) and a key inflammatory protein (called C5a) that are elevated in patients with MND and linked to distinct disease presentations. This project will investigate both monocytes and C5a in healthy volunteers and MND blood, and identify alterations in genes and cell functions. This will provide important information that could help accelerate the progression of novel drugs targeting these factors.

ALS Quest

You are invited to participate in an ongoing research project that is looking for risk factors that might precipitate motor neurone disease (MND). An online anonymous questionnaire asks a series of questions about you that may give clues as to what factors trigger MND.

Everyone is welcome to complete the questionnaire - people with the sporadic form of MND (that is, the type that does not affect other family members), people with familial MND, relatives and others without MND. Please note, if you have previously submitted a response to the ALS Quest questionnaire, there is no need to complete it again.



The questionnaire, designed by Dr Roger Pamphlett at the University of Sydney, and instructions for how to complete it can be found at www.alsquest.org.

The survey works best in a Firefox browser. If you are having problems accessing the survey contact the researchers directly via email als.quest@sydney.edu.au

This study has been approved by the Ethics Review Committee (RPAH Zone) of the Sydney Local Health District.

Motor Neurone Disease Association of NSW

Christmas Orders 2019 - Support our fundraising efforts - stocks are limited.
Click the item to view online and place your order



Presents
"Best Wishes for a Merry Christmas and a Happy New Year"



Australian Baubles
"Wishing you all the Best for the New Year"



Decorative Star
"Warmest Greetings of the Season and every good wish for the Coming Year"



Peace, Joy and Happiness
"To wish you Peace, Joy and Happiness for Christmas and the New Year"



Aussie Animals and Santa
"Season's Greetings and Best Wishes for the new Year"



Christmas Pudding
1kg Pudding Made by Pudding Lane



Keyring Torch



Shopping Bag



Socks
Ladies - Purple
Mens - Navy



Photo Frame
Brushed Aluminium.
Engraved with MND NSW logo
205mmH x 153mmW
(to suit 4"x 6" photo)



Plush Puppies
Black & White, Tan & White, Cream, Black



Dog Bandana



Motor Neurone Disease Association of New South Wales

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 <http://fb.me/mndnsw> ABN 12 387 503 221

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

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And
many
valued
volunteers