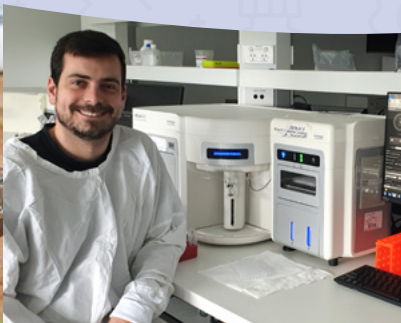


How you can
Fundraise
and help support MND
research in Australia



mnd 
Research Australia

A World without MND

Welcome

#TeamMNDResearch

What is MND?

Motor neurone disease (MND), also termed Amyotrophic Lateral Sclerosis (ALS), is a degenerative disorder of motor neurones of the central nervous system. MND is one of the most rapidly progressive and devastating neurological disorders, typically resulting in death within 2-3 years from symptom onset. The disease causes progressive muscle weakness, communication and swallowing difficulties and respiratory failure. In some cases, MND also results in behavioural change and dementia. MND currently carries a 1 in 300 lifetime risk with more than 2000 people currently living with MND in Australia. The prevalence of MND is anticipated to worsen globally, with a 69% increase forecast in the next 25 years.

At present, there are no high efficacy treatments to slow or stop the relentless progression of MND.

Thank you for Fundraising

Thank you for choosing to fundraise for MND Research Australia and to support researchers around the country who are working hard to discover a cure, find effective treatments and to improve the care of people living with MND. We really appreciate all of your fantastic efforts raising funds for MND research.

Are you planning on participating in a sponsored event, such as a challenge event, or do you want to do your own thing? Regardless of your choice, this guide is put together to share with you some hints, tips and guidelines to help you reach, or even smash, your fundraising target while at the same time having fun – after all it's called FUNdraising!

Raising money takes a lot of effort whether you're running an event at work, school or in your community. And if you're taking part in a challenge event then you also have to train hard too! Thankfully, #TeamMNDResearch consists of experienced fundraisers who have completed many successful challenges and helped hundreds of individual and community fundraisers across Australia.

Your passion to make a difference in the world of motor neurone disease (MND) is encouraging. We are grateful and want to support you to the best of our capabilities.

Thank you for your efforts and please contact us with any queries that are not answered within this guidebook.

Your fundraising team.



MND Research Australia is the research arm of MND Australia. Every fundraising and donation dollar received by MNDRA is used to support the work of MND researchers across the country.

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We can *help* your fundraising stand out from the crowd!

Today's fundraising environment is very competitive, which is why we have put together a few items to get you on your way to becoming a successful fundraiser. We have information about MND and posters that can be ordered to use at your event (please contact MNDRA to receive their current resources list).

What fundraising materials can you expect?

When you notify us that you are going to raise funds to support MND research we can provide you with:

- * Information booklets about MND
- * Posters
- * Social Media promotion

Use of MNDRA Logo and name

Incorporating the MNDRA logo on your fundraising materials indicates that your event has been approved by MND Australia and that funds raised will go to MNDRA for research. We can supply the logo upon request once your event has been approved and we have been advised on how it will be used. You must submit a copy of its attended usage for approval before publication.

Taking part in a challenge event?

Whatever the challenge event – marathon / half-marathon / cycling – we would be happy to review application of our logo on your clothing items so you can stand out from the crowd and your supporters can easily recognise you.





**MND
FACT**

MNDRA has injected over
\$45 million
to fund MND research
across Australia

I know I want to **fundraise**, but what *and* how?

You have decided you want to fundraise, but what to do?? Here are some ideas to consider – maybe you can do all of them over twelve months!! Regardless of whether you do one or many, small or large, we want to support you because every cent raised will help support Australian research into MND.

Don't forget, many of these suggestions can become “virtual” events potentially reaching more supporters.

MND FACT

Research has proven that effective use of non-invasive ventilation (NIV) can improve patient survival by more than a year





Tried and true fundraising ideas

- * Take part in a challenge event in your city – there are so many to choose from and there’s one to suit every fitness level!
- * Have you been growing your beard / hair for many years? Now you have a reason for changing your look by shaving it all off! Make an event of it and get your family and friends to donate to the cause. Add an extra incentive by letting the person who made the largest donation be the one who shaves off your beard /hair.
- * Organise a Drink Tea for MND (or a Martini for MND) – this is a great fundraising activity which can be done at home, work, community hall or park.
- * Have a bake sale
- * If you belong to a sporting club, see whether they will support you in an MND Fundraising Competition day where teams donate to participate. You can also include a BBQ, auction, merchandise sale, and raffle
- * Hold a Trivia Night / Cocktail Event / Ball
- * Seasonal Fundraising Event – why not add a “theme” to your fundraising event? Some seasonal events that lend themselves to theming include: St Patricks Day / Valentine’s Day / Easter / Christmas.
- * Depending on your location you could run an AFL / NRL Grand Final event / Spring Carnival event / Melbourne Cup Day / regional Cup Day.



Some suggestions for ‘grown ups’ events

- * Ginuary – imagine the wonderfully refreshing Gin cocktails you can have in Australia’s January, February or any time sun!
- * Brunch with a fizz
- * Cocktail competition – enlist your favourite cocktail makers and have a competition for who can make the best “blue” cocktail
- * Martini for MND



Not to forget our younger supporters

We are often asked how school students and teachers can be a part of the search for a cure. Here are just a few ideas:

- * Fancy dress or dress down day at school
- * BBQ at lunch time
- * Wear blue for MND Day
- * Mute me for MND



**MND
FACT**

1 in 300 people
will be diagnosed with
MND in their lifetime

Whatever you choose, you will be supporting the best Australian researchers who are searching for answers on cause, treatment and cure.

Bringing a fundraising activity to life

You have given this a lot of thought and now you want to bring a fundraising activity to life. The best way to raise awareness and money is by getting your family, friends and networks involved. If you have a good story and a unique event, you may even attract local media. We can provide you with relevant information and statistics if requested by Media. Here is a checklist to get your fundraising started.



What can I do?

Check out our inspirational Tried & True fundraising ideas.



Where will the event take place?

This depends on the activity. Things to consider – will it be indoors or outdoors? Capacity? Parking? Public Transport? Disability Access? Cost? Plan B if outdoors and weather is bad?



When can I hold the event?

Check whether any big events are happening in your area – can you piggy-back on them or will they clash? If you need key people, are they available?



Who will come and who will help?

Use your own family, friends and other networks to promote the event, as well as social media. Make sure you provide all the details – when / where / cost / public or invite only. If it is a family friendly event, it is recommended that it be an alcohol-free event.



What entertainment / attractions do I need?

This depends on the event and it is important to explore costs and any local noise / environment regulations.



Will I need insurance / licenses / local council permissions?

If you are holding your event in a local council venue you most likely will need permission. See page 22 for more information on keeping your event legal.

I know what I want to do, but how do I raise money from the event?

This is where the hard work starts. Here are some suggestions:

Sell tickets

This is one of the main ways to raise money from your event. Decide how much it is going to cost to run the event, i.e. venue hire / food & beverage / entertainment / promotion and add an additional amount to that as a donation. Be sure to sell as many tickets as possible in advance, then you are guaranteeing donations even if they don't turn up on the day.

Get Sponsorship

If your event is going to involve members of your local community, you may be able to get sponsorship support from local businesses. Many businesses are also open to sponsoring and supporting their employees' fundraising efforts so be sure to approach your management and offer them options to donate in return for acknowledgement in any promotional materials.

Raffles and Auctions

Silent and live auctions really encourage competitive bidding and it is amazing how much someone will pay for a simple item when they know that they are supporting a special cause. Raffles are also a great fundraiser. You could go for a theme: a basket of garden items or maybe a pamper pack? Are any of your friends foodies or wine buffs? By getting items from a number of sources you can put together a great raffle. You will need to check the licensing rules in your state to decide whether you can sell tickets beforehand or only at the event.

If you are holding a dinner or ball you could offer a table raffle or sell the centrepiece to the highest bidder.

Remind people why they are at your event

This might seem obvious, but it is an opportunity to pass on information about motor neurone disease and why you're passionate about raising funds. Share your story – what made you want to do this? Distribute some MND flyers (available from MND Australia about the vital need to raise funds to examine the potential cause of the disease. If you have a loved one living with MND ask them if they are comfortable with sharing their story, as this is a very visual way of demonstrating why you want to make a difference. MND Australia may be able to organise for a researcher or staff member to speak about current research at your event.

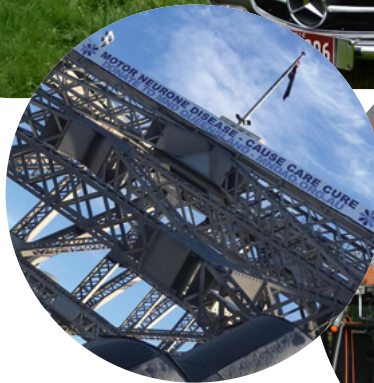
**MND
FACT**

MND is terminal.
Average time from diagnosis
to death is 2-3 years



What can you do to make it a FUN fundraiser?

When someone goes to an event, they want to have a good time. This could be catching up with old friends, hearing their favourite songs, learning a new game or enjoying great food. Whatever it is, the more fun people are having the more inclined they are to donate and to support your future events.



How many ways can you say Thank You?

There are many ways to do this – at the event make sure that any sponsors are acknowledged in print, in presentations and in any speeches. It is also important to thank everyone who attends – because without them the event will not be successful. And don't forget how important it is to let everyone know how much was raised by the event and how these funds will help people with MND.



#TeamMNDResearch

Stories



MND FACT

“Named” research grants are funding MND researchers throughout Australia

Rockoff MND

Rock Off MND was inspired by Jenny Simko who was able to attend the first event in 2016. Sadly Jenny lost her battle with the disease but her family and friends are committed to making sure this is an annual event that supports vital MND research.

Shag Gregory Memorial Poker run

In 2021, the 22nd annual ‘Shag Gregory Memorial Poker Run’ was held in Hay. The event is a vintage and veteran motorcycle and car club run, with lunch, drinks and a BBQ dinner at the South Hay Hotel at the end of the day. It is a fantastic community day and a fabulous way to raise funds for motor neurone disease research.

Judy Mitchell Memorial Long Lunch

In November of 2019, the Rotary Club of Nelson Bay organised and held the ‘Judy Mitchell Memorial Long Lunch for MND Research’. The event included a silent auction, a raffle and a live auction. The money raised from this luncheon was enough to allow for the award of a ‘named grant’ in 2021. The Judy Mitchell MND Research Grant was awarded to Dr Victor Anggono from the University of Queensland.



Walk to D'Feet MND

If you're not yet ready to organise your own fundraiser why not take part in one of the many Walk to D'Feet MND events that take place throughout Australia. Walk to D'Feet MND events are the major fundraising activities underwritten by the state organisations and they provide vital funds to ensure ongoing service delivery to people with MND as well as help fund research. Registration is easy and you can participate individually, with family and friends or get a team together to support someone you love who has been impacted by MND. Walk to D'Feet MND events allow people impacted by MND to come together in a safe and friendly place. Walk to D'Feet are not challenge events, they are suitable for all ages and ability.



Tough Mudder Events

Tough Mudder events are an ultra-endurance obstacle race often beginning at 8pm and finishing at 8am the following morning. The goal is to complete as many 8km loops including obstacles in the twelve hours, with merely a head torch to guide the way.

Depending on where you live, Tough Mudder events can take place in gruelling conditions, sub-zero temperatures and rain, adding to the already difficult task. However, at the back of the minds of those taking part for MND, is how insignificant this struggle is compared to those directly affected by MND which is why they want to raise funds for research so that new treatments may be found to improve their quality of life.

School Fundraisers

Just one way in which school students are supporting their state MND organisations. We've seen students from Primary and Secondary schools holding Gold Coin Days / Wear Blue Days as well as hosting morning teas.





Marathons around the globe

Marathons are a way of life for some and it can be a great way to raise awareness and funds for MND research.



Golfing across Australia

Golfing is a well established activity and one that provides many opportunities for people to raise funds for MND. These events, like the annual Tee Off MND at Clifton Springs Golf Club raised \$20,000 for MND research.



**MND
FACT**

The people of Benalla have been raising funds to support MND research grants since 2008 each year funding one or more Mick Rodger Benalla Research Grant

Sporting Club Events

Sporting Clubs are amazing supporters of their members. Clubs across all codes and throughout Australia are frequently running events to raise funds. Often a club will nominate a special MND Challenge Day with proceeds from games, raffles, BBQ and auctions donated to their state organisation. Some go the extra mile and organise for special MND colours for their uniforms.





Heather Harris and her knitting

Heather Harris is a long-term fundraiser for MNDRA. For the last four years, Heather has been knitting teddies and blankets that she sells through her facebook page 'Teddies for Motor Neurone Disease Research'. Every dollar that Heather raises goes directly to MND Research Australia. Heather originally started knitting teddies when her mum came to live with her after she was diagnosed with MND. Although her mum had lost her voice due to MND, she was still able to use her hands, so knitting became an activity they could do together, instead of sitting down for a chat. Not only does Heather donate her time, but she also buys all of the materials at her own cost.

**MND
FACT**

Every day in Australia
2 people are diagnosed
with MND

Capturing the car enthusiasts

Old Cars / New Cars / Luxury Cars / Muscle Cars – all have contributed to awareness and fundraising for MND research. It is clear that there are car enthusiasts everywhere and many of them are committed to supporting research into cause of the disease. This is particularly so for those who have a family history of the disease.



**MND
FACT**

More than
2,000
people have MND
in Australia

Get your **FUNdraising** *under way*

Ready – Set – Go FUNdraising!

Our experienced fundraisers and supporters have shared a few tips with us on how you can raise more money from your fundraising activity. Here are some to get you started, but remember we are always ready to help with more ideas and practical tips.

How much will you raise?

This is often a dilemma – especially for first time fundraisers. Consider how much you would like to raise and set that as your target. Setting a target keeps you motivated throughout your journey and it gives your supporters a goal. Many fundraisers set their target and are surprised how quickly it is reached and how frequently it has to be increased.

Your supporters may be able to claim a tax deduction

All donations over \$2 are tax deductible, providing they are a donation and that the donor is not receiving anything in return. See our section on “legal do’s and don’ts” for more information.



All of the research funded by MNDRA comes from donations

Make it easy for your supporters to donate

Your fundraising will be easier and more successful if you create a fundraising page. This is a fantastic way to tell your story – why you are raising funds for MND - and you can share your fundraising to family, friends and colleagues regardless of where they live in Australia or overseas. We know that personal stories, especially those that include photos, inspire people to support you as they can see your passion, and whenever someone makes a donation they can send you a message of encouragement. Plus, donors automatically receive a tax deductible donation receipt – what could be better than that?

Contact MND Australia for information on how to set up your online fundraising page



Thinking big? Have someone special you want to honour?

If your fundraising activities raise \$50,000 or more, MND Research Australia will award a named grant of \$100,000 in the subsequent funding round, by topping up the additional \$50,000 from general revenue. As the donor/fundraiser, you get to choose the name of the grant. To see the grants allocated each year, including those named grants that have been awarded as a result of the amazing fundraising efforts of our supporters, visit <http://www.mndresearch.org.au>.

MND FACT

The prevalence of MND is anticipated to worsen globally, with a **69% increase** forecast in the next 25 years

Promote your Event



Social Media – a FUNdraisers best friend!

As the saying goes, “a picture is worth a thousand words” and this is especially true with social media! There are many advantages to using social media to tell your fundraising story – it’s easy, quick and a powerful way to spread your message and gather support. Social Media enables you keep your family and friends updated on each milestone of your fundraising journey.

Remember that to get the best out of social media your posts need to be eye-catching, so get creative! Short videos can be created using your smart phone. Why not do a live broadcast of your event and share your day. Facebook and Instagram stories are great for this.



Make the most of your hashtag

Hashtags are a recent phenomenon that increase awareness of your fundraising. Combine your unique hashtag with your state organisation’s hashtag so your supporters can be inspired by your posts as well as learn more about MND.

Tag us so we can keep up to date on your events

MND Australia is active on Facebook, Twitter and Instagram see below:

-  www.facebook.com/mndaustralia/
-  [@MND_RIA](https://twitter.com/MND_RIA) (MND Research Australia)
-  [@mndaustralia](https://twitter.com/mndaustralia) (MND Australia)
-  www.instagram.com/mnd_australia/





Newsletters / Organisation Web sites

MND Australia publishes an eNewsletter and we welcome the opportunity to promote your planned fundraising activity whenever possible. We also love to receive photos and feedback about your event so we can publish these as a thank you and to inspire others to take up the fundraising challenge.

Visit the MND Australia page at www.mndaustralia.org.au to sign up



Posters / Invitations

If your event is being held in your local community, workplace or school you should consider designing a poster that can be displayed in shop windows or notice boards and invitations which can be handed to potential participants. Remember to include the important details: Event name | date and time | venue | cost | contact details &/or website | RSVP (if required) organisation logo and a sentence about why you are holding the event.



Finally, say *Thank You!*

**You can never say Thank You too many times!
Saying Thank You to your supporters lets them know you
value them. Saying Thank You may also inspire and
motivate others to become Fundraisers!**

The **Do's and Don'ts** you need to *know* about **Fundraising**



Fundraising should be an enjoyable experience for you and your supporters. We want to do what we can to keep it that way but there are some important fundraising rules and regulations that must be followed to keep you and MND Research Institute safe.

As each state may have different rules and regulations around fundraising we ask that you contact MND Australia to talk through any specific activities you are doing. We have summarised a few important items following:

Raffles

Rules around raffles vary in each state and it is important that you check with MND Australia if you are planning on having a raffle as part of your event.

Public Liability Insurance

Once you contact MND Australia they will be able to advise you on what public liability insurance they can offer you. If your event is taking place at a venue, such as restaurant, their public liability insurance may cover you. It is your responsibility to check with the venue.

Food and Drink

Like raffles, there are different rules around service of food and drinks at events. MND Australia should be able to advise you regarding this. If you are selling alcohol you definitely need to ensure you meet all regulations regarding the safe serving of alcohol.

Receipting

MND Australia can provide a receipt for any event payment as long as you can provide the name and address details.

Goods purchased at events are not donations under the tax law. Only donations can attract a receipt that is tax deductible.

If you collect a lot of cash or cheques from people who do not want individual receipts, you will receive a receipt in your name for the total amount. This will not be a tax deductible receipt.

**MND
FACT**

MNDRA has awarded over
350 MND
research grants
to Australian researchers





How else can I be involved?

You have finished your fundraising event and you still want to be involved to help raise awareness of the need for research into cause, treatment and cure of MND.

Tax Deductibility

What portion of the donation is tax-deductible?

Donations of \$2.00 and over are tax-deductible. Some people at your event might want a receipt to allow them to claim the donation against their tax.

If the amount paid at your event includes an amount for something that the person has received in return for their payment, this part will not be a claimable tax deduction. For example, if they received a meal as part of the ticket price, only the balance will be receipted as tax deductible.



Paying in your funds raised

Your fundraising efforts are greatly appreciated. If you set up an on-line fundraising page through MND Australia then there is nothing more you need to do as the funds will automatically be transferred to their nominated bank account.

For fundraising events that do not use an on-line fundraising page, funds can be paid into the organisation via mail, bank transfer or your credit or debit card. Details for all these options are available from MND Australia.

Advocacy

Although motor neurone disease affects approximately 2,200 Australians each year it is not well known or understood by the wider community, particularly the high care needs of people during their disease progression.

The financial cost of MND is huge and while most Australians aged under 65 when diagnosed can access support under the National Disability Insurance Scheme (NDIS) those over 65 when diagnosed can only access support from MyAged Care. Currently this support is totally inadequate and, due to the large waiting list for funding packages, many people with MND die without ever receiving any funds. By joining the MND Australia Make Aged Care Fair campaign you can help raise awareness and eliminate this age discrimination.

It is easy to add your voice:
www.mndaustralia.org.au

Named Research Grants

Rock Off MND

'Rock Off MND' has funded research into MND through the Jenny Simko MND Research Grant since 2016. The idea for 'Rock Off MND' was conceived by Jenny Simko herself, who was diagnosed with MND in 2014. Each year through Jen's inspiration, 'Rock Off MND' raises substantial funds from a series of events for MND research, funding a total of nine MND research grants from 2016-21.

Since 2016 the Jenny Simko MND Research Grants have supported have supported researchers at the following institutions:

- * The Florey Institute of Neuroscience and Mental Health, VIC
- * Western Sydney Local Health District, NSW
- * University of Queensland, QLD
- * University of Melbourne, Vic
- * University of Sydney and Westmead Hospital
- * Institute for Breathing and Sleep, VIC
- * University of Tasmania

Mick Rodger Act to D'Feet MND

The people of Benalla have been raising funds to support MND research grants since 2008. 'Benalla Act to D'Feet MND' events feature walks, bike rides, golf days, ice bucket challenges and the Benalla Superball to raise money. The group were amongst the first to support a 'named' grant for MND research. This 'ownership' of a grant gives a sense of identity with the research and the researcher and leads to continuity with the determination to continue this support each year. In 2008 when the Benalla group had its first fund raising event there were only three named MND research grants. This concept was encouraged and attracted other groups and individuals to raise enough money to underwrite a named grant. The Benalla community has had an incredible impact on MND research in Australia.

Recent recipients of Mick Rodger Act to D'Feet MND grants have supported researchers at the following institutions:

- * University of Wollongong, NSW
- * University of Sydney, NSW
- * Florey Institute of Neuroscience and Mental Health, VIC
- * University of Melbourne
- * Macquarie University



Betty Laidlaw MND Research Grant, zo-ee MND Research Grant, Jenny Barr Smith MND Collaboration Grant

The development of copper-ATSM as a treatment option for MND started around 17 years ago when it and related compounds were tested in animal models of neurodegenerative disease. Over the years, the laboratory-based evidences supportive of copper-ATSM being an effective treatment accumulated to the extent where clinical testing in MND patients became a legitimate possibility. Following a successful Phase 1 trial, a larger Phase 2 trial has recently been completed and we are keenly waiting to hear the outcome of this study. As a result of the generous support Motor Neurone Disease Research Australia receives from their donors, more than \$1.2 million has been invested to support three projects that aim to assist developing copper-ATSM as a potential therapeutic. These projects are:

- * Betty Laidlaw MND Research Grant,
- * zo-ee MND Research Grant,
- * Jenny Barr Smith MND Collaboration Grant

MNDRA General Grants

Through 20 years of research, Professor David Berlowitz and his team at Austin Health have demonstrated that the effective use of non-invasive ventilation (NIV) can improve patient survival by more than a year. This is currently the most effective treatment available for MND patients. NIV is the process of providing patients with respiratory support without using invasive artificial airways such as tubing. Instead, oxygen is delivered via a face or nasal mask from a mechanical ventilator, known as an NIV machine. MNDRA funded this research in 2010, 2017, 2020 and 2021 and recently Professor Berlowitz and his team received funds of \$3.48 million from the Medical Research Future Fund, to improve the uptake of NIV technologies.

Grant Mackenzie Research Grant

Associate Professor Thomas Oxley and his team from the Vascular Bionics Lab at the University of Melbourne have developed a computer interface that will help people paralysed by MND communicate again. Stentrode™ has been developed as a brain-computer interface to record brain signals that can help people generate text with their thoughts without the need for speech, writing or other forms of communication. The software development and computer interface were funded by MNDRA with a grant named in recognition of a \$100,000 donation received from Grant Mackenzie who was living with MND in WA. At the time of Grant's very generous donation he was rapidly losing his ability to speak due to the increasing paralysis of the muscles controlling his speech. A recent trial demonstrated that Stentrode™ could help MND patients operate a computer through controlling the mouse through their brain-computer interface

Superball XI MND Research Grant (Masters); Betty Laidlaw MND Research Grant

A recent publication by MNDRA-funded Melbourne researchers has identified an immune pathway that may play a key role in the neuroinflammation seen in MND and present a novel target for developing new treatments. They found that by blocking an immune sensor called STING, they could dramatically prevent inflammation from MND patient cells, paving the way for a new class of drugs to be developed for people with neurodegenerative disorders, such as MND.

The discovery, published in the journal *Cell*, on the 8th October 2020, was led by Walter and Eliza Hall Institute who collaborated with colleagues from the University of Melbourne, the Hudson Institute for Medical Research and The Florey Institute of Neuroscience and Mental Health. Some of the research was supported by MNDRA.

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-  www.mndaustralia.org.au
-  www.facebook.com/mndaustralia/
-  [@MND_RIA \(MND Research Australia\)](https://twitter.com/MND_RIA)
-  [@mndaustralia \(MND Australia\)](https://twitter.com/mndaustralia)
-  www.instagram.com/mnd_australia/

Thank You
for Fundraising
and being so amazing!



A World without MND