

# MNDnews

The newsletter of the Motor Neurone Disease Association of South Australia



- What's new at the Walk to D'Feet MND this year?
- Meet MNDSA Board Member, Stephen Pisani
- Take a journey through the Simpson Desert with Magoo's Crew

Until there's a **cure**, there's **care**



# Message from the CEO

With Easter behind us, we all look back and wonder where the last three months went! MNDSA offices have been a hive of activity and we are excited to share our latest update with you in this edition.

As Matthew Massy-Westropp our Client Services Manager retires we take the opportunity to welcome Kerry McMullan onboard in the key role of Director of Care Services. Kerry has a wealth of experience as you can see on Page 3 and is a fantastic addition to our team as our services continue to evolve. I would also like to take the opportunity to thank Matthew for his diligent service and the foundations he laid that will assist in the growth of our association and the services we can offer.

The recruitment market has been extremely challenging over the last three years in our industry, but I am delighted to announce, after an extensive search for over 12 months, that MNDSA have our inaugural Speech Pathologist on our team. This area was identified as a vital gap years ago and a donation from Geoff Thomas OAM (retired Chairman of MNDSA) and government funding has helped bring this opportunity to life. Melinda Gentle brings a wonderful skill set for our community and is already out making a difference with our clients' communication needs.

Volunteers are also vital for MNDSA to remain viable which is why we have recently appointed a full time volunteer coordinator on staff. Olga Russo is here not only to ensure the success of our current initiatives with the Talking Grief and Life stories projects, but will also be expanding the opportunity for volunteers to support our various events and office roles to ensure we can continue to thrive and support our community. Our Talking Grief support program is now active and expressions of interest are now being taken for people wanting help to document their Life Stories.

The first quarter has seen us planning a huge line up of events and initiatives for the year ahead – all the latest details can be found on page 14.

It is exciting to see the registrations rolling in for our 2023 Walk to D'Feet MND event as well as the planning that is going into making the event even better this year, with many new enhancements!



We thank major fundraisers who have taken their time to support us on Page 7. Special mention to Ella Fleming who rode on a Bike from Adelaide to Melbourne, retracing a journey documented by her Uncle Phil who passed away from MND years ago – an amazing achievement.

We have a number of corporate sponsors who get behind us whose details are shared on page 11. Also, if you have been to Bunnings Edwardstown on a weekend you may well have seen the sausage sizzle in support of MNDSA. These have been managed by our Larapinta Trekkers who have already raised over \$23k of our \$100,000 target for our Trek in August. More details on Page 15 or you can support them via this link <https://mnDSA-larapinta-2023.inadv.com.au/>

MNDSA is continuously advocating to raise awareness of Motor Neurone Disease. We are looking forward to welcoming Premier Malinauskas and Minister Picton to meet members of our community at our Walk to D'Feet event. Last month we also had the opportunity to catch up with Minister for Human Services Nat Cook (pic above left) and Erin Thompson MP (pic above right), Member for Davenport. They have both been wonderful supporters of our work and community and we encourage you to contact your local MP if you would like to shine a light on the needs of people with MND.

Wishing you all a pleasant Autumn and looking forward to seeing many of you alongside us in your 'Never Give Up' Beanies down at Pinky Flat on 30 April 2023.

Tough journeys are not meant to be walked alone. At MNDSA we work hard to ensure that you'll never walk alone as we strive to ensure our community gets the support they so desperately need.

Thank you for the part you play in that support.

**Until there's a cure, there's care.**

**Karen Percival**  
CEO

# MNDSA Staff Update



## **Kerry McMullen, Director Care Services**

Kerry has been a Registered Nurse for over 30 years, starting in the Royal Adelaide Hospital Intensive Care Unit. During this time she developed a passion for 'all things neurological' and began studying and then teaching neurotrauma at Adelaide University. Moving to Victoria she began teaching at RMIT University managing an undergraduate Bachelor of Nursing Course and teaching in Medical Sciences.

Kerry has completed an executive master's degree in business and has extensive experience working in commercial health sectors. While working in the private health insurance sector in Sydney she built a successful health subsidiary company whose purpose was to support clients with chronic disease management and hospital substitute services. During this time she commenced a master's degree in Neuroscience – further indulging her passion and fascination for all things neurological. Living back in Adelaide and joining MNDSA is the start of a new chapter.

## **Melinda Gentle, Speech Pathologist**

Melinda has extensive experience primarily working with adult clients with acquired neurological conditions in both inpatient and community based rehabilitation settings. She has also provided clinical leadership as the Lead Speech Pathologist in her most recent health setting. Melinda is a passionate advocate for communication as a fundamental human right and is excited to lead the new Speech Pathology service for MNDSA. Her focus is to support people living with MND to access the tools and resources to maintain effective communication with the people around them.



## **Olga Russo - Coordinator Volunteer Programs**

Olga is a Qualified Social Worker with over 12 years' experience in the aged care sector. Previously she has worked in a Pastoral Care Role alongside Volunteer Coordination enabling her to provide social and emotional support to clients and their families in a palliative care environment. She is excited to be working at MNDSA and using her skills and knowledge to build our volunteers for programs, office support and events so that we can assist and support as many clients and their families as possible.

## **Caleb McMullan - Warehouse Officer**

Caleb has recently joined the team and has a background in youth work, trades and as a Youth Pastor giving him significant experience in communicating with people of all ages. After becoming aware of a family friend who was diagnosed with MND, he is eager to bring awareness and support around MND with the equipment he can deliver to our community. He values the opportunity to work for such a worthy cause.



# Living with MND

**We asked our Inaugural MNDSA Speech Pathologist, Melinda Gentle to share a few details about her role and how it will help people living with MND.**

## **What is Speech Pathology?**

Being a Speech Pathologist means I am an Allied Health Professional who can assess, diagnose, and manage communication disorders. I can help you:

- when you have trouble understanding and talking with others.
- with reading, spelling and using technology or other ways to communicate.
- assess, diagnose, and manage swallowing disorders, which can make eating and drinking difficult.

## **Speech Pathology and Communication**

MND can cause weakness in the tongue, lips, vocal cords and breathing muscles which can result in changes in the ability to speak. This can cause feelings of frustration, isolation and loss of control. I can work with you to explore different tools and strategies to support your communication needs and to help you to maintain effective communication with those around you. This may include:

- Specialist assessment of your communication
- Information about communication strategies and aids
- Access to communication devices and technologies
- Communication partner education and training

## **Speech Pathology and swallowing**

MND can also weaken the nerves and muscles used for eating, drinking and swallowing. People living with MND may experience difficulties with chewing and safely passing food and drinks through the throat and into the stomach. This can cause problems with nutrition and hydration, chest infections and difficulty participating in mealtimes with others. I can work with you to manage swallowing difficulties and support your nutrition and hydration which may include:

- Regular assessment of your swallowing ability
- Recommending food consistencies to make food and drinks easier and safer to swallow
- Education about safe swallowing and mealtime strategies



*MNDSA Client Jim with MNDSA Speech Pathologist Melinda*



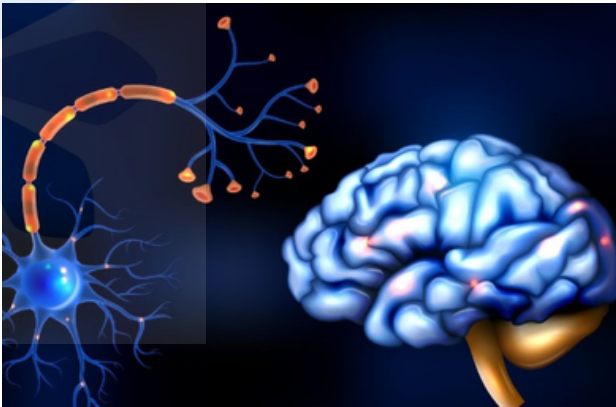
*MNDSA Client Tanya and speech assistant App on her mobile*

## **How can you find out more?**

To get started or request more information please call the MNDSA office on 8234 8448 and ask to speak to Melinda.



# MND Education & Research



**State of Play** is a Webinar Series organised by MND Research Australia (MNDRA). The webinars began in 2020 and are open to all members of the MND Community to provide an introduction to the advancements of the research community in Australia. MNDRA would love to hear any suggestions regarding topics for future webinars, so if there is an area of MND research that you would like to see covered then please email MNDRA at [research@mndaustralia.org.au](mailto:research@mndaustralia.org.au)

To review past webinars or to register for upcoming webinars, click this link:

State of Play | MND Australia  
or scan the QR Code:



## 34th International Symposium on ALS/MND

The International Symposium is the biggest annual conference dedicated to ALS and MND research. Each year this symposium brings together researchers from around the world to share new understanding of amyotrophic lateral sclerosis and motor neurone disease. This year's event will take place in Basel, Switzerland on 6-8 December 2023. For more information visit: [Home - International Symposium on ALS/MND \(mndassociation.org\)](https://mndassociation.org) or click the QR code below:



## Would you like to contribute to MND Research?

Flinders University PhD Researcher and speech pathologist, Rebecca Francis is interviewing people with MND and their carers about swallowing, cognitive and behavioural change in MND patients. Participants will receive a \$40 gift card for their time. Participation will involve one 30-minute interview with Rebecca online, on the phone or in person. The closing date is Tuesday 30 May 2023.

To find our more contact:

**Rebecca Francis**

**Ph 08 8201 2811**

**Email: [rebecca.francis@flinders.edu.au](mailto:rebecca.francis@flinders.edu.au)**

SA Health Human Research Ethics Committee  
approval: ID4660



**Monday, 28 August 2023**  
**The Florey, Melbourne**



MND Australia together with MND Victoria are hosting the next National Care Conference in Melbourne with a focus on addressing psychosocial aspects of care, providing care in a complex setting, partnerships in caring and building intellectual knowledge and capabilities. For further information, please click the QR code above.

# Giving Advance Care Planning Australia

BE OPEN | BE READY | BE HEARD



Advance care planning involves planning for your future health care. It enables you to make some decisions now about the health care you would or would not like to receive if you were to become seriously ill and unable to communicate your preferences or make treatment decisions. It gives you the opportunity to think about, discuss and record your preferences for the type of care you would like to receive and the outcomes you would consider acceptable. Advance care planning helps to ensure your loved ones and health providers know that matters most to you and respect your treatment preferences. The QR code will take you to the Advance Care Planning website which is an excellent resource for the complex topic.

## Creating a Will

We have listened to the voices of our clients who have told us that dealing with the practicalities of planning for life's end can seem overwhelming and complicated. That's why we have teamed up with Willed to bring you a simple, affordable, quick online solution to making your Will using the QR code or by visiting <https://www.willed.com.au/mndsa>

Willed is one of Australia's leading online estate planning platforms, built by lawyers and trusted by thousands of Australians. With Willed, you can write your legal Will online in less than 20 minutes from the comfort of your own home.

For just \$159 and in three easy steps you can have a will that is legally valid throughout Australia and customised just for you.

You will be asked to create a Willed account, answer some questions about your partner and children and appoint your executors.

After you have taken care of your loved ones, you might also like to consider leaving a gift to MNDSA. Large or small, when you include a gift to MNDSA in your will you are making a serious impact in the availability of care and support for people affected by a diagnosis of MND and the search for better treatments and a cure for MND.





# MNDSA Thank You



## Riding for Phil

Ella Fleming is an emergency nurse and a novice cyclist. Since she was young, she has wanted to recreate the ride that her Uncle Phil completed (Adelaide to Melbourne) before his battle with MND. To date, Ella has raised just over \$11,600 and completed her journey on the 27th of March after a phenomenal effort. She is donating these funds to MNDSA to support the MND community in SA. Thank you Ella, the team at MNDSA think you're amazing!



## Jamestown Apex Club

The Jamestown Apex Club and the Northern Areas Council tackled the town's excess recycled water issue which has now become a significant community fund raising activity. Life member of the Apex Club Deane Simpson was diagnosed with MND when he was in his 60s. His family greatly appreciated the support that MNDSA provided him during his battle. The club has also shown their appreciation to MNDSA, by donating \$5,000. Thank you to everyone at the Apex Club in Jamestown.



## Balnaves of Coonawarra

This special winery on South Australia's Limestone Coast has created an innovative way to give back to charities that are close to their hearts. Instead of adding their wine tasting fees to their revenue, they generously donate this income to various charities throughout the year. We are proud and grateful to be one of the charities and recently received a \$5,800 donation. Thank you Balnaves of Coonawarra. Great wine made by great people!



## CMV Group Staff Foundation

MNDSA would like to extend a big, heartfelt thank you to the team at CMI Toyota Christies Beach, via their CMV Group Staff Foundation. The Foundation, which is funded by voluntary contributions from the staff from CMV Group businesses recently celebrated 15 years of giving. To further celebrate this milestone, each CMV Group business was given the opportunity to give a grant to a local charitable organisation. MNDSA graciously received a \$3,500 donation earlier this year. This generous donation will help to support our MND community in SA.



# Sponsor Spotlight

## Pisani Property Group & S&S Developments



***An update on these corporate philanthropists, who are donating a portion of the profits from the sale of one Townhome in their current development project to MNDSA.***

### **What brought the Pisani Property Group & S&S Developments together?**

S&S Property Developments and Pisani Property Group were brought together through a mutual interest in developing high-quality real estate projects and a shared passion to deliver an exceptional service for our clients. Both companies have a strong track record in the industry and share a common vision for creating innovative and desirable properties that meet the needs of our clients. The partnership between S&S Property Developments and Pisani Property Group allows us to combine our respective strengths, expertise, and resources to deliver exceptional property projects. Together, we are able to leverage our collective experience to create projects that are not only visually stunning but also functional. Both companies are committed to providing our clients with the highest level of service and satisfaction. By joining forces, S&S Property Developments and Pisani Property Group are able to offer our clients a more comprehensive suite of services and greater value for their investment.

### **What was the catalyst for deciding to support MNDSA?**

Pisani Group has been supporting MNDSA for over 5 years. With Stephen Pisani being a Board Member at MNDSA and knowing the struggles of the organisation and the cancellation of the major fundraisers due to COVID, we thought it was great to be able to offer support in a significant way.

Donating a portion of the profits from the sale of one Townhome in our current development project at Kurralta Park, was a great way to support a worthy cause and make a difference in the lives of people living with MND and their families.

**Tell us a bit about the new property development, where MNDSA will be a beneficiary?** We are constructing 23 Townhomes with our boutique builder Techné Build. Our main aim was to create a product for our clients that was price sensitive and also a product they would love to call home. Those who have decided to purchase as an Investment will also benefit from its desirable location being so close to the city and the surf, providing the ultimate lifestyle.

### **When is the project due for completion and what are the plans for the sale?**

Completion of the project and handover of the properties to their new owners is anticipated to be around Christmas 2023. Slight delays have occurred due to lack of building supplies which is all too common in SA, however, we have managed to source materials from less conventional outlets to enable us to complete this project within an appropriate timeframe for all parties involved.

In regard to our sales, Pisani Property Group have sold 22 of the allocated 23 townhomes, all sales being achieved off market and prior to any foundations being poured, a phenomenal result achieved by our sales partner. This leaves us with the final sale where a portion of the profits will be donated to our MND mission.



**Stephen Pisani (L) and Steven Vacca (R)**



**What industry suppliers have supported the development and the charity aspect of this project?** We are currently contacting all of our suppliers and trades to see if they would like to donate to this great cause. We would hope that some of these suppliers and trades see our aspirations to help those who may not have as much assistance as others and join us in helping out in this special project. Any help from suppliers will be greatly appreciated and graciously accepted on behalf of MNDSA - a little bit goes a long way.

**MNDSA Chairman, Scott Penhall and his late wife, Anna have a special connection to this project, tell us more?** As the chair of the board and as a friend, it was a great opportunity to be able to create a permanent tribute to honour the life of Anna Penhall. The naming of "Anna's Lane" within the development, will be a permanent reminder of the legacy she leaves behind and for her family to treasure forever.



**Scott Penhall, MNDSA Chair, with his late wife Anna Penhall and their three children.**

**Will there be a launch event to mark the opening of Anna's Lane?** Yes! We will organise a launch at the completion of the development. Anna's lane will be officially open, and we will hand over the keys to the special purchaser of the final Townhome. A portion of the profits will then be generously donated to MNDSA.

**Share with us why philanthropic giving is so important to you?** All of the companies involved in this development hold key values, including that of love, giving and impact at the core. Impact first, clients second, profits third. We believe in helping others where we can, to honour loved ones that have passed and to make a difference to those who need help the most.

**What other charities do you support in SA?** Whilst Pisani Group support over 40 not for profit organisations across all sectors, and have done so for over 20 years, this is the first philanthropic project for S&S Property Developments and the start of many more to come.



# Join together at Walk to D'Feet MND 2023 on Sunday 30 April



Our annual Walk to D'Feet MND event symbolises the hope that one day we will defeat this devastating disease, the resilience of our community who are currently battling MND, and also honours the memory of those whom we have lost.

There's still time to register and join us on Sunday 30 April, as we walk 4.5km around the beautiful Torrens River Precinct, celebrating our community's strength, courage and unity.

Your feedback from last years' event has been taken on board! We have added some extra elements to the event to make this day an even bigger and better experience and listed below are just some of the things you can expect to enjoy on the day.

- Hon. Peter Malinauskas, Premier of SA official welcome
- NOVA919's Breaky Host, Jodie Oddy as MC
- Hon. Chris Picton, Health Minister in attendance
- Erin Thompson, MP Member for Davenport
- Live Acoustic Duo 'Driving Doris'
- Caledonian Pipe Band
- Ice Bucket Challenge
- Moorish Bites, Moroccan Street Food
- Cheese and Wine Marquee
- Two Deja Brew Coffee Vans
- Solo walkers meeting place
- Children's activities and much more!



## Event Details & FAQ's

**When:** 9am - 3pm Sunday 30 April 2023. The walk starts at 11am sharp.

**Where:** The lawns of Pinky Flat, War Memorial Drive, North Adelaide SA

**Who:** Everyone is invited; our MND community, family, friends, colleagues, sponsors, media and special guests.

**How:** Participants can walk, wheel, bring prams, bring canine friends and most of all, have fun!

**Why:** To gather as a community, express hope and raise vital funds for ongoing care and support services.

For further FAQ's visit:

<https://my.mndsa.org.au/page/93/faq-for-the-walk-to-dfeet-mnd-2023>

OR click the QR code



## Online Tickets

Each ticket includes a #NeverGiveUp Beanie and entry to the event.

Individual - Adults (Age 13+)	\$40
Individual - Child (12 and under)	\$25
Group Registration (10 people)	\$350

## To Register or Donate:

<https://my.mndsa.org.au/events/49/walk-to-dfeet2023> Or click the QR code:





# The Walk to D'Feet MND 2023

## Corporate Sponsors



The Team at Paradise Mazda have been supporting MNDSA for the past couple of years; largely with vehicles for the Client Service team and most recently, as MNDSA's Flinders Trek Sponsor. We can't wait to welcome Paradise Mazda as one of our main event sponsors for the 2023 Walk to D'Feet MND, as they're bringing a strong contingent from the Paradise Mazda office and showroom to show their significant support for our MND community at the event!



**SA MUSHROOMS**  
*delicately hand picked*

The owners and management of SA Mushrooms have been supporting MNDSA for many years and always welcome the opportunity to do more when they can. Having experienced the devastation of MND first-hand, they are committed to helping MNDSA maintain ongoing support for people living with MND in SA. We welcome SA Mushrooms as one of our main event sponsors of the 2023 Walk to D'Feet MND and we can't wait to fly their flag at the event on 30 April.



We welcome Claymore Wines as MNDSA's wine sponsor at the event and they will be showcasing their aptly named 'You'll Never Walk Alone' wine brand to our community. We are thrilled to welcome Claymore Wines to the NEW Cheese & Wine Marquee this year and hope this collaboration is the start of many more events to come.

Claymore Wines is a boutique winery located north of Adelaide in the Clare Valley and was established just over 20 years ago offering small volumes of Grenache and Riesling from a single vineyard in Penwortham. Since then, the estate has grown to include additional varietals and 44 hectares across three additional vineyards in Watervale. \*Source: [www.claymorewines.com.au](http://www.claymorewines.com.au)



# Personal Story

## Simpson Desert Bike Challenge - By Dan McGuire



**Dan McGuire & Mel Ferry (above)**

*My Mother-In-Law Cheryl Ferry passed after a short, brave battle with MND. MNDSA were there to support us, and we wanted to "give back" to others diagnosed with this disease. Cheryl loved the Simpson Desert and although I had never done this type of bike trip before, as a keen "road" cyclist, I trained hard for the challenge. There are 21 other riders, and each with their own crew. We rode approx. 100kms per day, and camped at night.*

### **How did you come to the decision to do this challenge?**

This had been a personal challenge that I wanted to do since finding out about the race in 2015. After crossing the Simpson Desert with Cheryl, Colin and some friends in 2020, the fire in my belly reignited and Mel and I decided the next trip would be on 2 wheels!

### **What impact on your normal lives did fitness training and all the other layers of preparation take?**

A very big one. Training started in 2021, when I signed up for the original race. When the race was cancelled due to Covid, Mel and I went across the Simpson Desert on the Madigan Line instead and found out pretty quickly that my training was seriously underdone. Fast forward to March 2022 and I started doing some research into cycling coaches. I found a coach that was able to give his time for 6 months towards training remotely.

Training was intense and comprised of 3 build weeks, followed by 1 recovery week. This happened 6 times before the race. In the build weeks I was doing upwards of 15 hours a week on the bike, either on the indoor trainer or outside on the weekends. Weekend rides would be anywhere from 2 to 4 hour rides per day. 15 hours a week doesn't sound like much, but when you take into account preparation (getting bike ready, getting gear on, making sure everything mechanically is fine) it sure takes a lot more. In addition as a fulltime principal at Leigh Creek Area School sometimes doing 50 to 60 hours a week, it was a lot!

Mel was a massive help, food and cooking is her thing and she made sure I was fed and watered. She also spent the weekends essentially being on call. We live in remote area so GPS tracking was used to follow along so that in the event of an accident, a puncture that couldn't be fixed or an unexpected need for more water or food, she knew where to go to find me!

If I didn't have Mel, there is no way I would have been able to give the time into the training that I did.

### **You raised the staggering amount of \$15,000 – how did you do it, and would you like to thank your supporters?**

We have an amazing group of family, friends and colleagues that supported us from day 1. It became a real buzz around Leigh Creek – where several other members of the community have had their lives touched by MND, as well as in certain parts of the Far North. Colleagues in Education and other schools helped out heaps, and even the amazing students from Ardrossan Area School (where Mel spent most of her schooling years and Cheryl worked) got involved.

We can't thank any one person, because it was clearly a team effort, every dollar counted, and a lot of people helped along the way, even if they didn't donate with cash to the cause. A super special thankyou does go to a beautiful friend of Mel's, Kate, from Denz and Co, who so very kindly donated 100 pairs of hand-made cornflower earrings that could be sold and all proceeds given to MNDSA.





**Was there anytime through the challenge, or the lead up to it, that were particularly difficult.**

2 weeks prior I broke the bike. With a world wide shortage of bike parts, and especially for fat bikes in 2022, it was always going to be impossibly hard to source parts. The anxiety levels were definitely elevated and we can't thank the team at Over The Edge Melrose enough for taking on the fatty and fixing it with 2 days to spare, those guys were amazing!

We also said 'no' to a lot of things. Friends birthdays, weekends out camping, special events. We didn't do any of our usual kayaking, hiking or adventuring like we'd do most weekends and for a while life was cycling, refuelling and work...and books...Mel read A LOT of books! We'd put enough pressure on ourselves that we simply couldn't fall sick and have the training compromised (which in a covid world, was tricky) and so much time was taken up with training that we struggled to fit everything else in.

**I very deliberately had a cornflower sticker put on my bike, so that when the times got tough, I could look down at it and remember who I was doing it for.**

**Were there any moments when you felt Cheryl was with you, particularly out in the desert, the area that she loved so much?**

For me, she was there the whole time. I never rode alone, and she always made sure I was pushing hard till the end. She didn't make it easy for me, but it wouldn't have been her style to do that. It was the same for Mel and Colin. Her presence was felt daily and she was a driving force with the whole adventure. We took photos because we knew she'd be on us if we didn't. She was so keen and on board with Dan's ideas that we knew her feedback and recap of the day was fed in though our own. Her voice was in the back of Mel's head during food prep (just a bit more, he'll be hungry) and of course ensuring that there was enough chocolate stashed in various places to keep Dan and Colin happy.



Mel also tackled the whole drive by herself. Colin was always the vehicle in front for guidance and then she knew she could draw on Cheryl's courage to know that she could get through the trip unscathed

We know she'd have loved to be right there in the vehicle with Colin, supporting her family members as she has always done so passionately. Luckily we had Colin there to bring that same energy and passion into the crew. Cheryl's soul may have left the Earth but she's with us every day, always.

**Moving forward do you plan to be involved in such a gruelling challenge in the future and what tips would you give to someone competing in it for the first time?**

The plans are in motion to be in the desert again with the fatbike in the nearish future. You can't do a race like that and only do it once. This time the pressure is off and we'll just be out there and enjoy the experience.

**Tips for young players:**

- Start your training early. If you think you're not doing enough, you probably aren't...
- Practise! Try everything twice to see what foods work for you and work out what sort of prep works for you
- Pick an awesome crew to come along and ALWAYS say YES to the adventure.

**Oh...and butt cream, a cyclist can never have enough butt cream!**

**HOW TO BECOME A FUNDRAISING CHAMPION?**

For ideas, tips and tricks on how to make an impact with fundraising for MND SA, visit: [MND SA - Fundraise](#) or click the QR code below:



# Upcoming Events in 2023



## Trekkers Trivia Night

Help the Larapinta Trekkers with their fundraising efforts and have an awesome night! Details Below:

- Friday 28 July, 6.30pm - 10.30pm
- Thebarton Community Centre
- Pizza (pre-order)
- BYO nibbles / Drinks for Sale
- Raffle, Live & Silent Auctions
- Special Guests
- Wine Wall and much more....

If you would like to reserve a table please call 08 8234 8448 or email [fundraising@mndsa.org.au](mailto:fundraising@mndsa.org.au)

For bookings scan the QR below or book via this link:  
<https://www.trybooking.com/CCBRI>



**Erin Thompson MP (R)**  
Member for Davenport  
2022 Trekkers Trivia Night

### CALENDAR OF EVENTS

#### Walk to 'Feet MND

Sunday 30 April 2023

#### National MND Week

Sunday June 19 - Monday 25 June 2023

#### MNDSA Trekkers Trivia Night

Friday 28 July 2023

#### Larapinta Trek

Wednesday 16 August to  
Monday 21 August 2023

#### Day of Hope and Remembrance

Friday 22 September 2023

#### MNDSA Gala Dinner

Friday 17 November 2023

#### MNDSA Client Christmas Event

Sunday 10 December 2023





# Meet our Larapinta Trekkers!

From 16-21 August, a group of Trekkers including the MNDSA Chairman and CEO will set off on the Larapinta Trail, NT, in the heart of Australia. This 6-day, 4-night adventure will see the MNDSA Trek Team traverse a total of 49kms amongst breathtaking scenery, making wonderful, life-long memories.

We asked some of our champion trekkers to share their 'why' for joining this challenge, and have outlined their inspirational purpose below.



**Karin Bell** (above)

I am trekking with my son Declan to raise funds for MNDSA and its vital role in supporting clients and families with MND. MNDSA were amazing in their support of our Gran and her carers in her MND journey. The funds raised then for MNDSA were used for her care, and now we would like to "give back" by fundraising now, so current and future people diagnosed will receive the same care and support.

For more information and/or to join our amazing group of Trekkers just scan the QR Code or visit <https://my.mnlsa.org.au/events/38/mnlsa-larapinta-trek-2023>



**Erin Thompson MP** (above)

I have seen first hand the support that MNDSA provide from the time my mother was diagnosed with MND in 2017, to her passing in 2020. I am happy to be a very active supporter of MNDSA, and am looking forward to this challenge, and raising vital funds for such an important cause.

**Kylie Barnes** (below)

As a support worker, I first came in contact with MND 2.5 years ago when I met Bruce, who had recently been diagnosed with MND and was grappling with the diagnosis and prognosis of this devastating disease. As I have supported Bruce in his home and the community, I have gained a greater appreciation of the effects of this heart-breaking disease. I feel honoured to be able to fundraise for a very worthy cause and as I pull on my hiking boots in training over the next 6 months, I will strive to achieve my fundraising goal of \$10,000.



To donate / support our Trekkers just scan the QR Code or visit <https://mnlsa-larapinta-2023.inadv.com.au>



INSPIRED  
ADVENTURES

# MND Client Services



## MNDSA's **CARE** pillars

We **Connect** people by offering specialist support coordination, information and advice, allied health and equipment services, as well as liaising with providers in health and community care.

We **Advocate** for people with MND to receive support services, regardless of age, when diagnosed and the disparity between the NDIS and Aged Care funding.

We support **Research** into cure and care and we **Educate** clients, families and the community about MND.



MND Information Sessions are designed for those newly diagnosed with MND. Our MNDSA Client Services Team members Denise Schoder and Leanne Shane will share information about MND and MNDSA's services, in a comfortable and informal environment.

Light refreshments will be available, and we encourage partners, carers and family members to come along.

Our team of occupational therapists (OT) led by Kesey Hean (pic above), work exclusively with our clients to support them with mobility, getting in and out of bed and chairs, communication and other key activities at home and in the community. OTs can arrange equipment options from our pool of items available for rental, as well as home modifications needed for clients to remain living in their own homes. Our Allied Health Assistants can follow up with clients and their carers to address specific training they may require.



Our Talking Grief Program is taking shape and several trained volunteers are now supporting people affected by MND. We continue to recruit volunteers to this program as well as anyone who may have skills to offer our Life Stories Program. For more information about these opportunities please go to our website and follow the links under Get Involved.

MNDSA's MNDEquip service continues to provide equipment and assistive technology to clients. The service supplies rental equipment and our staff will deliver, install and collect items as well as provide information about its correct use.



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