

Spring 2022

MNDnews

The newsletter of the Motor Neurone Disease Association of South Australia



The sun has set on the inaugural
2022 MND SA Flinders Trek

mnd 
South Australia

Until there's a cure,
there's care

MESSAGE

from the CEO



This Spring, I have great pleasure in sharing that MNDSA is experiencing even greater growth with new team members, new community events and many new initiatives that will bring ongoing benefits to our MND Community.

Firstly, I'd like to thank everyone involved with fundraising over the past few months. The increasing number of community events being held has been wonderful to see and MNDSA has seen a marked uplift in funds raised by our dedicated community members.

These community fundraising events take effort and passion and we're so grateful for members of the community who get involved and make a meaningful contribution.

We are fortunate to also welcome two MNDSA Ambassadors to support our ongoing efforts to raise awareness of MND, raise the profile of MNDSA, and to bolster our fundraising potential.

Recently Brad Ebert, co-owner of Hey Diddle Wines and former Port Adelaide Football Club player has joined us as an ambassador and is already making a valuable contribution. Hey Diddle Wines has made a commitment to donate \$5 from every bottle of their 'Pinot Gris for MND' from the 2021 vintage. In addition, Brad helped to create an awareness video to support our recent Flinders Trek.

Andrew (Cosi) Costello, from *South Aussie With Cosi* also helped spread the news about our inaugural trek and this resulted in strong community support and a welcome boost to funds raised. We are just coming up to hitting our fundraising target of \$100,000 for this event which is truly astounding and a testament to our amazing Trekking Group.

Together with our Client Services team, I'm also so pleased to share that we are embarking on the 'Life Stories' program, with the pilot 'Life Story' memoir completed and the process well underway to recruit volunteers to support this program so it can be an ongoing and enriching offering for our clients.

We couldn't do it without the support of SA Power Networks Employee Foundation, who donated \$15,000 to help bring the project to life and of course our valued volunteers, lead by Alan Hickey, who is driving the Life Stories program for the benefit of our community.

We're also preparing for the 'Talking Grief' loss, grief and bereavement program to get underway and have started the initial stages of communicating with potential volunteers.

'Talking Grief', together with our new information sessions, commencing in October will provide additional support and information for our clients and their family, which we hope will make an important difference in processing and coping with the impact of MND.

Last but not least, I experienced first-hand, the wondrous and emotional journey of the recent Flinders Trek. I am so grateful to have shared this challenging, but amazing adventure together with the 9 other MNDSA Trekkers. We put one foot in front of the other every day to support our MND community. It was a privilege. Join us on our journey pages 14 - 16.

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

Karen Percival
CEO

MNDSA Staff

MNDSA is excited to welcome more new staff members to our Association, only made possible by the recent SA Government funding, as well as donations from our community.

Lisa Clarke joined our team in August in the role of Talking Grief Project Officer. Lisa brings a wide range of experience dealing with grief and bereavement in her previous role at SA Cemeteries, and additionally, is a qualified counsellor. Lisa will be responsible for establishing the Talking Grief project which will recruit and train volunteers to provide support to our community dealing with loss, grief and bereavement. Lisa will also be providing a boost to our volunteer coordination generally as we look to grow opportunities for volunteers across the board.



Leanne Shane joined MNDSA in September as an MND Advisor. Leanne works in our team supporting clients aged 65 and over, as well as adding valuable expertise to expand our services for people needing support with their communication needs. This new service will support people with complex communication needs by providing advice, strategies, training and access to low and high tech equipment. Leanne has a range of skills from a career working in various areas of disability, and more particularly technology which will be of huge benefit to our clients.

Jessica Cook joined MNDSA in October and is expanding our occupational therapy team to three. Jess has had a career in disability, working with people who have neuro-degenerative conditions such as MND. She has particular expertise and interest in people being able to continue doing the things that are important to them, with the use of access technologies in the home and community. This additional capacity will enable the team to provide more support to our clients ages 65 and over.



Kate Burgun joined MNDSA in July in a new role of Partnerships & Fundraising Manager. This role is an essential part of our strategy to ensure that MNDSA can be sustainable into the future. Kate is a senior Business Development, Communications and Marketing specialist with over 20 years of experience in the NFP, Government and Corporate environments both in Australia and overseas.

Sarah Best has joined MNDSA as our new full-time Administration Officer. With a great deal of experience in a range of administration roles, she is very much looking forward to meeting our community and supporting our Client Services team.



Personal Story Geoff Both

In April 2020 we received the terrible diagnosis. Jenny had been having trouble with her ankle for months; after a minor strain it just didn't get better.

X-rays and ultrasounds showed the ankle was structurally sound, but Jenny could no longer lift her foot. 'Drop foot' they called it. After ruling out numerous other possible causes, nerve conduction tests showed Jenny had MND.

We left the specialist's room in disbelief, went home and wept. We wept for the life we would no longer have together, for Jenny not living long enough to see her grandchildren grow up, and for her fear they would not remember her.

Jenny had lived a life full of friendships, travel, and purposeful work as a dental hygienist. Above all, she loved being a mum to Sophie and Henry. She kept fit and exercised regularly, and after diagnosis she kept going to the pool and doing as much exercise and physio as possible.

After being diagnosed the first thing to do was tell family and friends. Jenny was determined to keep living as normally as possible. She was definite on one thing, she did not want any pity, and she was not going to be self-pitying.

What happened over the next two years was amazing. We saw the best of human nature as all the love and kindness and care Jenny had showed to others throughout her life came back to her over and over. Almost daily people visited, bringing food, thoughtful gifts, or just their presence to show they cared.

In particular, Sophie visited often with her son Remy, and with husband Jack for weekend swims in the pool. And Henry would come every Thursday night and carry Jenny into the spa, where the buoyancy made her most comfortable.

Henry and his wife Kelly would also bring the twin girls around as often as possible. While Jenny did not live to see the grandchildren grow up she got to see their early years close up.



One of our aims was to look after Jenny at home as long as possible. As she went from using a walking stick, to using a walking frame, to being wheelchair bound, and in the later stages unable to lift a fork or spoon, I had great help from Jenny's sister Bronwyn in looking after Jenny 24/7. When she could no longer stand we used a sliding board to move her from bed to bathroom to wheelchair to armchair. And when that became too difficult we used a hoist/lifter.

All through this time MND SA was with us, providing advice and equipment. The occupational therapists were helpful in anticipating what we would need next and getting us the right equipment, while Peter visited us in the van numerous times bringing various equipment and aids. With the help of the Association we were able to make Jenny as comfortable as possible at home for as long as possible.

The end came 26 months after diagnosis. Jenny's final three days were at Laurel Hospice where she received palliative care that eased any distress. Those last three days gave all the family a final time to tell Jenny what she meant to us, and also to read to her the many loving messages from friends.

She died peacefully late at night, with Bronwyn holding one hand and me the other, wrapped in the certain knowledge that she was loved.

Geoff Both
August 2022

Living Better

MNDSA Life Stories Program

Everyone has a story to tell. Why not help people living with MND tell their story?

MNDSA is planning to introduce a Life Stories Program where clients can share their story, and have it compiled into a memorable hard-cover book – so their story will last forever. The Life Stories Program is generously sponsored by the SA Power Network Employee Foundation – a long running supporter of MNDSA.

The process will begin with several recorded interviews with the client which will then be transcribed, edited and laid out in a professionally hand-bound unique Life Story book. Two copies are provided at no cost to the client and they may choose to pay for as many additional copies as they wish.

One of our clients, Greg Downton and his wife Jean took part in the pilot of the Life Stories Program with the volunteer coordinator of the Program, Alan Hickey.

It resulted in a fantastic book which Greg and Jean have shared with family and friends, and helped MNDSA learn how to make the process work smoothly for our clients.

MNDEquip

MNDSA Allied Health Assistant Angela Burnett introduces OBI Robotic Feeder

OBI is a robotic self-feeding device that can help people with MND who have difficulty feeding themselves to endine with greater independence. Meal times are a meaningful activity for many and introducing the OBI can re-establish the social experience of eating and reduce the load of carers.

The OBI features a robotic arm that is controlled by activating a switch with any part of the body, with a carer to set up the OBI and pre-prepare the food. The OBI allows users to select between four compartments of food and command when the food is scooped up with its spoon and delivered to the mouth. Meaning, you can choose what you eat and the pace you want to eat at.

If you are interested, please contact the team at MNDSA to trial this device on 08 8234 8448



SAPN Employee Foundation CEO Vicki Shearer with Partnerships & Fundraising Manager Kate Burgun

To launch the Life Stories Program, we need the support of volunteers and we have the following exciting new roles for those interested in volunteering and MNDSA client's family members:

- Interviewer, Transcriber & Writers (combined roles)
- Researchers
- Photographers
- Proof-Readers
- Designers
- Artist/cartoonists

Please scan the QR Code to register your interest in volunteering for this program



Join our Life Stories Program as a Volunteer!

MNDSA Thank You

MNDSA Trekkers Trivia Night was a total sell-out!

What a wonderful fun night our 350 Trivia Night guests had at the Thebarton Community Centre on Friday 12 August. Huge thanks to our MC's Rosa Matto and Alan Hickey who kept the evening flowing with creative challenges, auctions, quirky quiz questions and other impromptu performances. Events like this take a lot of work behind the scenes. Thanks to our amazing Trekkers and volunteers for all your work in bringing it together, and to all the trivia guests who got right in to the spirit of the night, thank you for your support - the final tally was an amazing **\$26,879**

Thank you to:

- Erin Thompson MP
- Rosa Matto
- Alan Hickey
- Karin Bell
- David Schultz and family
- Tracey Watters
- Gayle & John Barry and family
- Nicola Massy-Westropp
- Anna and Troy
- Peter Smith
- Stewart Tremain and Family
- Rose Senesi
- Meredith and Hayley Henderson
- All prize donors
- All volunteers



MNDSA Tax appeal

We would like to thank everyone who so generously donated to our tax appeal this year. The final tally was \$19,441 which will go towards providing vital services to people in South Australia living with MND. Special thanks too, to Greg and Jean Downton (pictured) for sharing their story with our community.



Barossa, Light & Gawler Umpires Association

MNDSA was again the charity of choice for this association and we greatly appreciate their ongoing support. MNDSA is very dear to the hearts of their Panel and in appreciation of the work we deliver, provide a donation to assist in vital research and treatment for people living with MND in South Australia.



MNDSA Thank You

Copley & Districts Gymkhana & Motokhana



The National Recovery & Resilience Agency Copley and Districts Gymkhana & Motokhana was held on Saturday 30 July and featured all manor of horse riding and motor bike challenges for all ages. A mighty \$7,000 was donated to MNDSA and we thank all who attended... Catch ya @ Copley!



Bruce shaving his head for MNDSA



This hero did wear a cape, to raise funds for MNDSA. Bruce's many supporters and local patrons enjoyed a great night at The Emu Hotel, Morphett Vale to support Bruce Smith, who chose to raise funds for MNDSA by shaving his head after seeing first hand the support we provide, through his much loved wife's journey with MND. Total funds raised \$5259



Magoo's Crew on the Simpson Desert Bike Challenge



The 5 day Simpson Desert Bike Challenge from Purni Bore SA to Birdsville QLD has now finished and MNDSA fundraisers Dan, Mel and Colin (known as Magoo's Crew) have well exceeded their target of \$10,000!

To read the inspiration behind their adventure AND the pledge made if they achieved their target (which has something to do with Dan and his beard pic left) go to:
<https://my.mndsa.org.au/.../magoos-crew-in-loving-memory...>

(donations can be made here also if you would like show your support)



MNDSA Upcoming Events

MNDSA AGM - Monday 21 November

The 2021/2022 MNDSA Annual General Meeting will be held at Thebarton Community Centre on Monday 21 November from 6pm. This provides a great opportunity to meet with our MNDSA Board Members (right), staff and get updates on the future

of MNDSA. Light refreshments will be available at the end of the AGM. For catering purposes, please RSVP via the QR code below.



The Ultimate Christmas Disco Party at The Arkaba Hotel - Saturday 17 December

Get your groove on at the 'Top of The Ark' on Saturday 17 December with well-known, local 10 piece band "No Two Ways". Doors open from 7pm and the entertainment commences at 8pm until late.

Included on the night will be:

- Live auction & raffle
- prize for the best dressed disco outfit

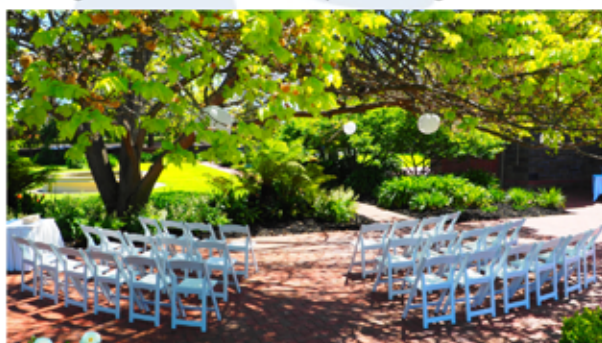
Tickets

- \$40 per person
- available from arkabahotel.com.au or via the QR code

All proceeds to MNDSA

The Day of Hope and Remembrance Service - Friday 18 November

This special afternoon is an opportunity to remember those we have lost to MND, to express hope for the future and to enjoy each other's company over some afternoon tea, in a tranquil setting. We will have the option to light a candle,



contribute to a book of remembrance, listen to readings and we are so pleased that the MC for the afternoon will be loyal supporter of MNDSA Mr Alan Hickey, who has conducted many of our events in the past and is heading up the Life Stories initiative.

- Partridge House Glenelg
- 1.30pm for 2pm start
- Refreshments will be served from 2.45pm
- Event concludes at 4pm
- RSVP 7 November 2022

Scan the QR code for more information and/or to book



MNDSA Upcoming Community Events



Team Not D'feated Annual BBQ - Freemont Park Saturday 15 October

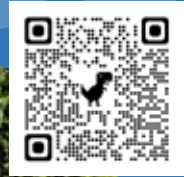
Team Not D'Feated are back raising funds for MND awareness and to support MNDSA.

You can meet this terrific group at their annual Sausage Sizzle:

- 10am - 1.45pm
- Fremont Park, Main North Road & Yorke Town Road, Elizabeth Park

Extra Activities:

- Raffle prizes
- Lucky Squares
- Cupcakes & Lolly Guess



Drouin Littlehampton Open Garden Scheme Saturday 5 & Sunday 6 November

- Open 10am - 4.30pm
- Entry: \$10 (U18 free) \$8 for certain concessions
- As EFTPOS facilities are not always available, cash is encouraged.

Extra activities:

- Morning/afternoon teas, plants, jams and jellies made from Drouin produce, raffle and other stalls.
- Owner will do a walk and talk at 11am and 2pm Saturday and Sunday.
- Visitors are welcome to bring a picnic to enjoy in the grounds.

The Adelaide Appeals Club Thanksgiving Wreath Party Friday 25 November



This exciting event will include delicious food and beverages from Jarmer's Room, a wonderful display of floral wreaths that will be available to bid for via auction, live entertainment, and will be an opportunity to give thanks with family and friends - to welcome in the festive season in style. For more information or to book just scan the QR code:

- 7pm - 11pm
- Jarmers Kitchen, The Jarmer Room
- 18 Park Terrace Bowden
- Christmas Wreath Auction
- Wine Sponsor - Bird in Hand



MND Research

A new Fellow, based at the Flinders Motor Neurone Disease (MND) Clinic, will oversee an exciting patient trial investigating the effectiveness of a drug combination used to treat HIV, in slowing the progression of MND.

Dr Alexandra Thompson has been appointed as the new Julie Lawrence MND Fellow at Flinders and will be involved in a worldwide trial called 'Lighthouse II', led by Professor Julian Gold of Macquarie University, Sydney.

Lighthouse II is the first phase three clinical trials in the world to use modern combination anti-retroviral therapy in patients with MND.

The COVID-19 pandemic slowed a lot of research across the world, and Dr Thompson said it was pleasing to get the third phase of the trial underway.

"Lighthouse II is a trial that involves people, it's not just looking at drugs in a lab. It's looking at whether a very well-known and frequently used combination of common anti-retroviral drugs used in HIV can have any impact on MND," Dr Thompson said.

"The trial is based on interesting research about some viruses that have been integrated into the human genome over millions of years, which are thought to be retroviruses similar to HIV. It's a placebo versus real drug trial and we'll be following the patients for two years to see whether it has any impact on quality of life, symptoms, and survival."

Established in memory of Dr Julie Lawrence – the first female plastic surgeon in South Australia – who passed away from MND in 2019, the fellowship will support Dr Thompson to care for people and their families living with MND and progress research at South Australia's sole MND clinic.

Julie's husband Steve and brother Graham made this fellowship possible, donating to the Motor Neurone Disease Association of South Australia (MNDSA) who have partnered with Flinders Foundation and the Flinders Medical Centre Clinician's Special Purpose Fund.

Dr Thompson is extremely grateful to receive the fellowship, which will incorporate patient care and research.

"It's not a matter of the funding making it easier, it's the difference between the research happening or not. Being able to fund a Fellow, like myself, as well as research coordinators, study coordinators, and research nurses is the only way it can work. It's imperative and central to the wheels turning. It's more than just important, it's essential."

"I've supported several patients with MND before, but only intermittently throughout my years of physician training, so to be able to come to a speciality clinic is a real privilege and something I'm very excited to be a part of," Dr Thompson said.

"It's also a great opportunity to get involved in research, which is something we all strive to do in our training, but it can be challenging finding opportunities or finding time to be involved in research."



Dr Alexandra Thompson

MND Research

“To be at a place where research is a central part of the day-to-day workings of the MND clinic, and planning for multiple trials on the horizon is fantastic. It’s great for my learning and experience, but most of all it’s fantastic for the patients.”

Dr Thompson will work closely with respected Flinders Medical Centre Neurologist A/Prof David Schultz, (pic top right) who is an experienced clinical trials physician and well-published in many areas within Neurology including MND.

Dr Thompson said research such as this wouldn’t be possible without generous supporters, like Julie’s husband Steve and brother Graham.

This research update is kindly supplied by the Flinders Foundation. Scientists at the MND Clinic at Flinders Medical Centre (pic right)



Save the date!

Sunday 7 May 2023

The most loved event on the MNDSA Calendar is The Walk to D’Feet MND, and we hope to make the 2023 event bigger and better than ever before.

Save the date, and stay tuned! Earlybird ticket sales will be on sale soon!



MND Estate Planning

Preparing a Will is one of the most important things you can do for yourself and your family. It will provide legal protection to your spouse, children and assets, and will also ensure your estate is handled according to your wishes after you have passed on.



MNDSA have teamed up with Willd to bring you a simple, affordable, quick online solution to making your will.

Willd is one of Australia's leading online estate planning platforms, built by lawyers and trusted by thousands of Australians. With Willd, 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 using Willd's convenient, safe, secure, and fast online platform. For more information just scan the QR code.



Having a current Will gives you and your loved ones peace of mind at an already stressful time.

People's Choice Community Lottery

1st Prize Toyota Kluger Hybrid GX RRP \$59,555	Early Bird Prize! 	2nd Prize Toyota C-HR GR Sport Hybrid RRP \$42,396
	3rd Prize Kosco Energy Solar Panel/Battery package RRP \$23,490	

Buy a \$2 ticket in the People's Choice Community Lottery to support us and go into the draw to win one of 43 prizes worth over \$300,000!

communitylottery.com.au

People's Choice
COMMUNITY LOTTERY

First Prize: Toyota Kluger Hybrid GX, RRP \$59,555. Second Prize: Toyota C-HR GR Sport Hybrid, RRP \$42,396. Third Prize: Kosco Energy Solar Panel/Battery package, RRP \$23,490. Buy a \$2 ticket in the People's Choice Community Lottery to support us and go into the draw to win one of 43 prizes worth over \$300,000! communitylottery.com.au

We are once again a participating charity in the Peoples Choice Community Lottery.

Every dollar from tickets purchased through the MNDSA page benefit our community. So you can donate to MNDSA and also have a chance to win a prize!!

Tickets are only \$2 each and there is a prize pool worth over \$300,000 AND an excellent Early Bird Prize too!

If you want to purchase tickets and support MNDSA, you can just scan the QR Code, and you are on your way!

Good Luck!



MND Advocacy

CEO's from all Australian MND Associations unite at Parliament House Canberra to advocate for improved support and for launch of Parliamentary Friends of MND Group

MND Australia also launched their new "Living with MND" Video:
<https://www.mndaustralia.org.au/articles/mnd-australia-launches-new-living-with-mnd-video>



The MND Network from all over Australia are continuously working hard to ensure the best care and support is available to every person impacted by MND.

On 8th September the Associations came together through their CEOs and gathered at Parliament House in Canberra to advocate for improved support for the 2,100 people currently living with MND in Australia, and those who will be diagnosed in the future.

We thank MND Australia and the Hon. Alex Hawke MP, for hosting a great and productive event and look forward to seeing positive outcomes following the launch of our Parliamentary Friends of MND Group, co-chaired by Alex and Senator Carol Brown. This is a group of Parliamentarians who are committed to advocating to improve the lives of all Australians impacted by MND.

In particular, it was incredibly moving to hear from three people living with MND who spoke at the event – Jason, Ron & Tania (who cares for her mum Roslyn). By sharing their experiences, in a room full of politicians and decision makers, they were able to raise awareness of the devastating impact of MND and their daily challenges using the NDIS and Aged Care systems. They also emphasised the vital importance of research investment to discover treatments and improve care.

Below: Parliamentary Friends of MND Group co-chairs by the Hon. Alex Hawke MP and Senator Carol Brown



MND Association CEO's - left to right Courtney D'Mello (WA), Karen Percival (SA), Graham Opie (NSW), Kate Johnson (VIC) and Stacey Thorpe (QLD) at Parliament House, Canberra



Right: Sharing lived experience with everyone present

FLINDERS TREK 2022

Memories by Tracey Watters

16 September 2022 finally arrived when 10 MNDSA Supporters would head off on the Inaugural Trek Challenge to Flinders Ranges.



Our committed MNDSA Trekkers from left to right: Karin Bell, Gayle Barry, Emily Evans, Clodagh Barry, Karen Percival, Tracey Watters, Scott Penhall, Jenny Kinlay, Stewart Tremain, David Schultz

Day 1

On a cold and wet Friday morning the trekkers set off from MNDSA Offices by bus for Ikara Wilpena Pound - the 'meeting place' of the Flinders Ranges with a real sense of enthusiasm and excitement that never waned throughout the entire trip. We were in expert hands. Guides Pablo, Geof and Inspired Adventures Tourism representative Kelsey worked hard to ensure that we had the very best experience possible.

After a coffee stop at Vault35 in Crystal Brook and an orientation talk from Pablo and Geof about what to expect on the next 5 days – it was back in the bus to our first hike – the Davey's Gully circuit located in the Mount Remarkable National Park. This fairly short loop, to test out our hiking legs, offered breath-taking views into the Alligator Basin and across Spencer Gulf where we could see as far as Whyalla.

Here, our guides introduced us to the importance and uses of the local fauna and how to identify bush tucker and bush medicine.



This was our first hike experience where we got close up to grazing wallabies and lots of bird life, not to mention plenty of goats. It was an opportunity to simply enjoy being present in the open air of the great South Australian outdoors.

From here we made our way to Quorn and then on through Hawker, finally arriving at Ikara Wilpena Pound Resort at 6pm which was to be our base for the next 5 days.

Trekking Distance 2.4kms

Day 2

Although we had a hike plan, we soon learnt that our enthusiastic and wonderful guides would offer additional short treks so as not to miss any spectacular and historically important sites.

Our first full day of trekking was a spectacular one. First up we went on a 'warm up' trek to Arkaroo Rock – a significant cultural site for the Adnyamathanha People to see the ochre cave paintings of the creation story of Ikara Wilpena Pound.

This was followed by our planned hike from Bunbinyunna Creek along the south-western escarpment edge of Wilpena Pound and up and over Bridle Gap into Wilpena Pound. This was a diverse hike; along a dry river bed, up and over old sheep tracks and pastureland, ascending and descending steep terrain, climbing up rugged rock faces to Bridle Gap. Having traversed over four peaks, we then made our way down to what turned out to be a rather meditative and quiet 8km walk across the valley floor compared to the mentally and physically tough morning.

The entire area was a haven for emus, kangaroos, and several species of native birds. Breath-taking is how I would describe Wilpena Pound. It is absolutely beautiful.

FLINDERS TREK 2022

As the day drew on, the group stretched out, and some of us were taking longer than others. It was a welcome sight for the 'tail enders' to see Guide Geof at the 3kms to go mark to revive the stragglers with afternoon tea. The 'tail enders' finally arriving back in the Pound just as darkness ascended around 6.30pm.

Trekking Distance 15.4kms

Day 3

We started off with a visit to Dingley Dell camp site where we walked among historical Malka (Art) Rock carvings and learned about the importance of megafauna to the Adnyamathanha people such as the quandong tree, rice flower, wattle seeds and Mistletoe (werteebee) tree.

After a short bus ride to historic Aroona Homestead, we started on our planned trek for the day which followed a well carved trail through the landscapes that inspired the iconic paintings of South Australian artist Hans Heysen.

Walking across the gorge floor and through valleys of pine forests this area was alive with wildlife. We sighted many Emus with their babies and looked closely at the evidence of the millions of years of geological history associated with this area. Returning to the bus, we drove through the breathtaking Brachina Gorge where we spotted lots of playful, curious yellow footed rock wallabies. Our scenic drive back through Bunyeroo Valley took us to Razor Back Lookout where the backdrop view of the Flinders Ranges was spectacular.

Trekking Distance 10kms

"The varying physical capabilities of the group were readily accepted and supported by the entire group" Associate Professor David Schultz, Head of Neurology, Flinders Medical Centre



Day 4

We headed to Angorichina Village to tackle the Blinman Pools Trek. Here we stepped across river boulders and what looked like well-designed slate pool tiles in their natural state. Encased on either side by huge red rock valley walls where we saw clever footed mountain goats, soaring eagles and stumpy tailed lizards along the way.

It was on a large and flat 'boulder' that presented the ideal location for us to pay tribute to the reason we were all on the Trek – 'the human logo' – each of us positioned to spell MND, (see below). It was not without some acrobatic photography from our guides that we got the shot.

This was a rather hot day so it was truly refreshing to know the pools would have plenty of water from the recent rains. Together we headed for the first pool where some brave swimmers enjoyed the chilly but refreshing waters whilst others headed on to the 2nd pool further up. Arriving back where we started at the village, it was a race to the ice-cream fridge at the village store.

Another impromptu highlight on the way back to the base was our visit to Wadna (means Boomerang) where 'Uncle Kristian' and his wife Gabby welcomed us to their collection of magnificent Aboriginal artefacts, carvings and paintings. Uncle Kristian shared with us the creation story and explained that Wadna is a place where local artists can display and sell their works.



FLINDERS TREK 2022

MNDSA CEO Karen became quite emotional when Uncle Kristian donated a painting for MNDSA to auction at our next fundraiser. Quite fittingly, it is a painting of Adnyamathanha bush medicine leaves from the Emu Tree, used for lots of medicinal purposes from relief of coughs and colds to pain, spiritual healing, and ceremony.

After saying goodbye to Wadna, we were driven to Hucks Lookout where on our final evening together we reflected on our reason for being a part of this experience.

Our guides served refreshments and nibbles as the sun set over the silhouette of Ikara Wilpena Pound peaks. It was a very emotional and special experience.

Trekking Distance 12kms

Day 5

It was time to leave the magnificent scenes of Wilpena Pound behind and begin our journey back to Adelaide. But not without some unscheduled bonus stops on the way.

First was Kanyaka Station Homestead to see the remains of one of the largest pastoral ruins of the Flinders Ranges, followed by a quick stop in Quorn to have some well-earned morning coffee and delicious cakes at the beautiful Quandong Café.

Just as we had started to unwind and relax our trek-weary feet, our wonderful guides diverted us to the stunning Alligator Gorge, accessible via 250 plus steps down to the valley floor and 250 steps back up again. Hard work but well worth the visit!!

Thank you to our Sponsors & Supporters

- Paradise Mazda
- SA Mushrooms
- Wadna
- All the amazing businesses that donated goods to our Trekkers to raise funds
- All of our generous donors



We then ventured on to Clare, on the promise of beautiful Bush DeVine platters and a glass of wine at Paulett's winery finally arriving back in Adelaide, where for the trekkers it was the long goodbye, with hugs all round.

Trekking Distance 4kms plus lots of steps!!!

No-one could have predicted just how inspirational this adventure would be. We all knew it would challenge our physical stamina, but none of us could have possibly estimated the remarkable bond that would eventuate between the group. If you are looking for an inspirational experience that transcends your usual excitement and sense of adventure we invite you to join the next MNDSA trek to Larapinta in August 2023.

"The entire MNDSA Team were on this journey with us. Everyone at the organisation was 100% on board with supporting us - our wave off and welcome home were truly very special"
Karin Bell, lost grandmother to MND in 2017

MNDSA Chairman & CEO

Scott Penhall & Karen Percival



Our 3 Outstanding Guides

Pablo, Kelsey & Geof



MNDSA LARAPINTA TREK 2023



Are you going to join us for the Trip of a Lifetime? Challenge yourself to tackle the Australian Outback with this bucket list experience, all in the name of supporting people living with MND.

Dates: 16 to 21 August 2023 - 6 Day trip, 4 day challenge

Fundraising Target \$3,500 per Trekker

Accommodation: Twin share in a 4-star hotel and comfortable swag camping

Difficulty: ranked 3/5 for ability

Trek across some of the oldest, unchanged lands in the world, with every step taken we'll raise vital funds to enable the best possible care and support to be delivered to South Australians currently living with MND and those are yet to be diagnosed in the future.

Testimonials from MNDSA Flinders Trek 2022

"It was such a positive experience I have signed up for the Larapinta Trek in 2023, and I would encourage all to consider joining future treks"

Associate Professor David Schultz, Head of Neurology, Flinders Medical Centre

"As a group we all faced and conquered things we never thought we could achieve"

Karin Bell, lost grandmother to MND in 2017

Save \$100 on your travel deposit when you sign up before October 31st! Sign up now and pay only \$375* as your first instalment (usually \$475).

For full details and to register just scan the QR code or visit <https://inspiredadventures.com.au/event/mndsa-larapinta-2023/>



MNDSA Corporate Sponsors

PARADISE MAZDA

The Mazda People



Paradise Mazda – Fundraising Trek Sponsors

Jeff Neale and the team at Paradise Mazda have shown their ongoing support of MNDSA by becoming Event Sponsors of the inaugural Fundraising Trek. Many months before the 2022 Flinders Trek started taking shape, Jeff and his team had already pledged sponsorship dollars to help get the event off the ground.

Fast forward to September 2022 and Jeff created a powerful awareness video, sharing his family experience with MND and his understanding of the vital services that MNDSA provides.

We thank Paradise Mazda for their valuable past and current support – to help MNDSA be the best it can be for the benefit of our MND Community in SA.

For more information on Paradise Mazda: <https://www.paradisemazda.com.au/>



SA MUSHROOMS

delicately hand picked

SA Mushrooms is no ordinary family business.

Having seen the effects of MND first-hand, the Owners of SA Mushrooms have been generously supporting MNDSA over the past 6 years with various donations, attendance at MNDSA events, and helping to support South Australians living with MND.

Most recently, they've been aware of MNDSA's inaugural fundraising trek to the Flinders Ranges and knowing they could make a major difference with their corporate donation, have contributed \$15,000 to help MNDSA reach their fundraising goal of \$100K!

We thank the team at SA Mushrooms for their ongoing kindness and support. Their significant contribution will make a tangible difference to our MND community and will help them to live better for longer with the support services, equipment, and care that they need.

For more information on SA Mushrooms: <https://www.samushrooms.com.au/>

MNDSA Ambassadors

Welcome to our new Ambassadors who are helping us raise awareness of MNDSA

Andrew (Cosi) Costello, South Aussie with Cosi

In August 2022, MNDSA engaged with well-known and loved SA media personality, Andrew (Cosi) Costello from Channel 7's South Aussie with Cosi. Cosi was thrilled to come on board with MNDSA to help raise awareness for the inaugural Fundraising Trek which took place up in the Flinders Ranges from 16-20 September and attracted 10 dedicated and courageous Trekkers who, collectively raised over \$80,000 to support South Australian's living with MND.



Cosi supported the Trek by creating an awareness video to share amongst his 300K+ social media followers. This video was also shared amongst MNDSA's social media and email community to help build hype around the event and to help generate fundraising support from the wider community in Adelaide and regional SA.

We'd like to thank Cosi and his team for their ongoing commitment to support MNDSA and our MND Community and you can join Cosi on his adventures here:
<https://southaussiewithcosi.com.au/>

Brad Ebert, Hey Diddle Wines

In August this year, MNDSA also approached Brad Ebert, former Port Adelaide AFL star and now co-owner of Hey Diddle Wines.

Brad is no stranger to MNDSA, having supported various fundraising events in the past – however he's pleased to come on board as one of our important Ambassadors moving forward to help raise awareness of what MNDSA does and help to raise funds for the vital services we continue to provide.

Brad has supported our Flinders Trek with an awareness video that has resonated well within our community as he lost his late Grandma to MND. Brad understands the challenges that individuals and families face when living with MND – and the importance of MNDSA's care and services.



To take his support one step further, Brad and the team at Hey Diddle Wines are donating \$5 from every bottle sold from the 2021 vintage of Pinot Gris. Known affectionately as the 'Pinot Gris for MND', we encourage our supporters and partners to try this beautiful, year-round wine – knowing part proceeds will benefit MNDSA.

You can order yours at via the QR code above and for more information on Hey Diddle wines go to:
<https://heydiddle.com.au/>

MNDSA Client Services

MND Education

It was clear that many people, early after their diagnosis, would like the opportunity to hear more about MND and how the Association can assist them.

Earlier in 2022, MNDSA worked with two fourth year OT students from the University of SA, Emma Giersch and Daniela Colotti-Perez, to understand how we can better engage with our clients, carers and community.

The students undertook a survey of our clients and carers, and spoke directly with MNDSA staff and others in the interstate MND Associations. Thank you to everyone who participated and provided us feedback.

Some of the key suggestions from the survey include MNDSA:

- communicating and promoting education and social support opportunities
- offering more social support opportunities (eg: peer support groups)
- considering ways to reduce barriers to accessing education and social support opportunities (eg: time constraints, accessibility)
- arranging group facilitators to be the driving force of sessions
- checking with the community about their preferences for education content
- Information on planning a Will

Now that MNDSA has increased our resources, we are getting ready to launch our new community and educations programs.



We are starting with "An Introduction to MND session" which will be held in the Thebarton Community Centre which is a fully accessible facility with parking on site. Initial sessions will be scheduled for October and November and facilitated by Matthew Massy-Westropp and Denise Schoder (pic above) with a plan to hold these every second month during 2023.

For anyone who is unable to join these sessions, we will make the information available subsequently.

Other initiatives that are planned include workshops for carers, and the introduction of an MNDSA organised online peer support group.

We look forward to welcoming you.

To see information on upcoming community sessions please head to our events page via this QR code or go to:
<https://my.mnlsa.org.au/events>



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