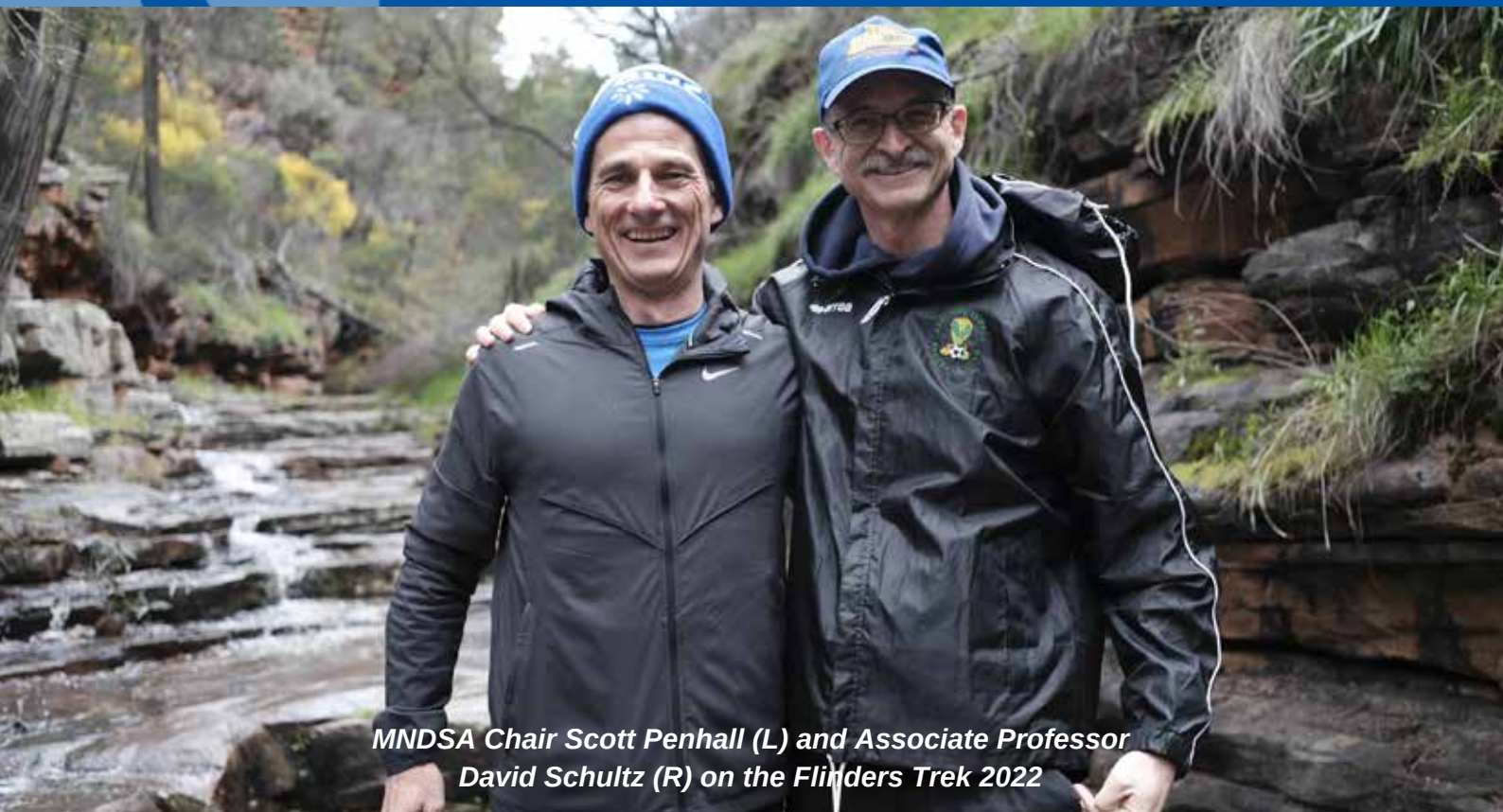


MND news

The newsletter of the Motor Neurone Disease Association of South Australia



MNDSA Chair Scott Penhall (L) and Associate Professor David Schultz (R) on the Flinders Trek 2022

- Getting to know Associate Professor David Schultz
- MNDSA's Larapinta Trek - are you up for the challenge?
- What's in store for MNDSA in 2023?

Message from the CEO



Welcome to the Summer 2023 edition of our MND news, and Happy New Year.

As we reflect on the year of 2022, it's fair to say that it was a year of solid growth.

The SA Government support for our clients that are 65+ commenced and we're already seeing the tangible benefits of this with record amounts of support hours delivered to clients by our team in recent months. We will be working to ensure our support for these families is consistent, state-wide.

Our advocacy efforts were also elevated following an important meeting in Canberra, with the Commonwealth Government at this meeting further acknowledging the needs of the Australian MND community by establishing the 'Parliamentary Friends of MND Group' initiative - giving MNDSA and other state associations a direct and ongoing communication pathway to raise important issues on behalf of our community.

I'm also thrilled to have welcomed many new staff members to the MNDSA team, all with valuable skill sets to help drive the association forward and continue our client-centric focus on care and support.

Our team genuinely cares about each and every client and their families. It's a pleasure to witness how much heart goes into what they do every day.

Last year was also a big year for fundraising and I was so pleased to see that MNDSA's events and community fundraising events reached new heights, both with the number of events held and also the funds raised.

These funds have helped start our new support service for clients needing help with communication technologies as well as ensuring we have enough vehicles to get out to our community.

The Board and I extend a huge thank you to everyone who has rolled up their sleeves and contributed to the overall fundraising efforts, as this is one of our most important income streams to maintain our vital services and research.

This thank you includes our valued volunteers of course, without whom we simply couldn't do what we do to support our MND community in South Australia.

The Board, Management and Staff are all excited to embark on 2023 to continue the momentum of the past year and keep doing what we love - helping our MND community.



We hope you enjoy this edition of MND news, read on to find out what's in store for us in 2023 and how you can get involved with our amazing and resilient MND community...

Our first and most loved event of the year, Walk to D'Feet MND is about to launch, and I look forward to seeing you all there on Sunday 30 April to walk alongside our community.

Until there's a cure, there's care.
Karen Percival
CEO

New Staff Update

MNDSA welcome our new Business Manager and newest Board Member and say farewell to a much loved MNDSA Warrior.



Suzanne Kennedy, Business Manager

I'm delighted to join MNDSA as Business Manager, working with the team to help deliver great services to our MND community. After 15 plus years working in the management of libraries and community facilities in local government, I am keen to use my business and operations management skills and understanding of MND to help make a difference in the delivery of MNDSA's vast array of services.

MND is close to my own heart after losing my sister in law to MND in 2003 at the age of 31. It is heartwarming to see the expansive array of supports now available to people with MND and I feel privileged to be a part of an organisation which helps facilitate the ongoing care, advocacy and support of people living with this disease.

Outside of work I spend my free time gardening, reading, spending quality time with my family and friends, walking our dog Stuart and caring for our backyard chooks.



Sue Wundenberg, MNDSA Board Member

Sue is an experienced senior executive with over 30 years within the building industry and a proven track record in Sales and General Management within CSR.

Sue's approach is team orientated leadership with a strategic awareness, possessing a high level of problem-solving capabilities, communication skills, and the passion and determination to get the job done at a high standard. A highly valuable skill set to bring to the Board!

Now semi-retired, Sue enters a new phase of her life as she is committed to "giving back" via volunteering and as a Director on the MNDSA Board.

Geoff Thomas OAM - Service to MNDSA

Geoff joined MNDSA in 2013 when his wife Mary was diagnosed with MND. He was a Board Member for 7 years and Chair for 5 years. During his time there was enormous development, with a new premises at Mile End, an expanded equipment pool, and an increase in staff to ensure services can meet the changing needs of people in a responsive, efficient manner. Geoff has represented SA nationally for 4 years, and through the Thomas MND Research Fund, supports research and services into care, especially as they relate to the wellbeing of the carer. MNDSA's new Augmentative and Alternative Communication support service will be part of Geoff's legacy.

Personal Story

A spotlight on Associate Professor David Schultz



Associate Professor David Schultz is the Head of Neurology and leads the MND Clinic at Flinders Medical Centre. His work with MND patients in SA and ongoing research (including clinical trials) is recognized internationally.

We'd like to recognise A/Prof Schultz as someone who is making a truly significant impact on the MND community in South Australia and beyond.

We spent some time talking with him to get a closer insight into his role at the MND Clinic, what he does to stay at the top of his field of medicine and, also, to learn more about why he's so passionate about supporting MNDSA and our fundraising initiatives.

What do you enjoy most about your role as Head of Neurology at the Flinders Medical Centre MND clinic?

The role as Head of Neurology at Flinders has many varied elements that I have to deal with in addition to my clinical workload, which adds to the enjoyment (but sometimes is a source of frustration!). This includes HR responsibilities, dealing with complaints, preparing reports and responding to other requests for information that come from various areas in and out of the hospital, as well as steering the department in teaching, research and clinical improvement initiatives.

My involvement in the MND clinic is the highlight of the week. Although we are dealing with a terrible disease, I am forever inspired by the grace and resilience of the patients and their carers.

I feel privileged to work with a wonderful group of doctors, nurses, and allied health staff who are all committed to providing a great service for those unfortunate to have the disease.

What are the greatest challenges you face?

Almost every day there is a new challenge or issue to deal with, but the greatest challenge is trying to maintain and grow the service in a financially constrained environment. We have been fortunate to have created an MND Fellow position to support clinic activity and participation in clinical trials as a result of a bequest to MNDSA from the estate of Dr Julie Lawrence along with contributions from the Flinders Foundation and Clinicians Special Purpose Fund. The bequest will soon run out and the other funding sources are not sustainable. However, we have found the Fellow position invaluable for the MND service, and so I am looking at ways to secure permanent funding for the position.

What are your hopes for future research?

The ultimate goal would be to find a curative treatment or discover what causes MND so that it can be prevented. In the interim, **I am hopeful that through the clinical trials that we are involved in now and in the future that we can find a more effective treatment or treatments than that which is currently available.**

What current clinical trial are you working on?

We are currently involved in 2 clinical trials. The first, Lighthouse II trial is investigating the potential benefit of an antiretroviral therapy currently used to treat HIV, the hypothesis being that viral DNA which has been incorporated into the human genome over generations may be one of the driving factors underlying MND. This is an international trial, being led by Prof Julian Gold, an infectious disease physician. The second trial, COURAGE-ALS, is another international multi-centre trial which is an extension of another trial that we participated in just prior to COVID, and is exploring the potential benefit of reldesemtiv, a molecule being investigated for the improvement in muscle function.



What would you say to someone with MND who is considering a clinical trial?

Involvement in clinical trials does require some extra effort on behalf of the patient and their carers, but generally patients involved in trials do better than those not involved due to the extra monitoring that occurs, even if the agent being studied proves not to be effective. Whilst the trial may not be of direct benefit to the patient participating, it will help to advance our understanding of the condition, and so ultimately will be helping others.

What was your favourite MNDSA fundraising event in 2022 and why?

Aside from the Flinders trek itself, my first experience in undertaking a Sausage Sizzle proved to be a memorable event, and despite the associated challenges was my favourite event. The day we volunteered for was the day of the weekend storm in mid-November. Along with my wife, father, and parents-in-law (so the average age of the group was about 75) we set up under grey skies with only a portable gazebo for protection at the Prospect Bunnings store. **At least the rain held off while we were setting up, but we were then exposed to intermittent electrical storms, tropical downpours and at the end of the day, gale force winds.** It was suggested by the Bunnings crew that we may wish to leave around 11am due to the inclement weather, but we stuck it out for the day, and were amazed by the generosity of the public in supporting us despite

the terrible weather. My family were amazingly resilient, especially my mother-in-law who was unfortunate to be on the receiving end of the gazebo roof reaching its limit for holding water, decanting its contents all over her at one stage mid afternoon.

What are you looking forward to during the MNDSA's 2023 Larapinta Trek?

There was great camaraderie amongst the Flinders trek group which meant that even those such as myself who were physically challenged by the trek felt supported. This trek will be even more challenging, but knowing some of those who have already signed up, I am sure that we will enjoy a similarly positive experience.

Lastly, what do you do to stay fit and healthy both mentally and physically?

The answer to both is by regularly attending the local gym. My routine is to be at the gym for an hour from 5.30am weekdays, where each day there is a new program laid out which incorporates a combination of aerobic and strength exercises. This helps me to maintain a reasonable level of fitness but also is a useful time to reflect on my plans for the day ahead.



Living Better with MND



MNDSA is delighted to launch our new AAC support service for our clients.

What is AAC?

The term **Augmentative** and **Alternative** Communication covers a wide range of techniques and communication aids that support or replace spoken and/or written communication. AAC is commonly used to refer to electronic communication aids and products (high-tech) but equally it includes simple, non-electronic (low-tech) options.

How can this service assist you?

Our team can work with you to explore and implement a range of tools and strategies to support your communication needs. We can also work collaboratively with your Speech Pathologist (if you have one). Our service can support you every step of the way from the initial meeting where we will work with you to establish your communication goals through to ongoing support and education.

Services Provided:

- Voice and Message Banking
- Voice Amplifiers
- Personalized Communication Boards and Flip Books
- AAC apps and software
- Equipment Hire including iPads, Eye Gaze devices and Mounts
- Education and Training (*individuals, families, professionals*)
- Ongoing Coaching and Mentoring

How can you find out more?

To get started or request more information please call MNDSA office on 8234 8448 and ask to speak with Leanne or Megan. Alternatively send us an email: aacsupportservice@mndsa.org.au



"Living with motor neurone disease - Aspects of care for people with MND, their family and friends" is an excellent resource about living at home with MND that is available from MNDSA.

Below is an excerpt from this publication:

During the days, weeks and months following an MND diagnosis, people often start thinking about how having MND will affect their plans and hopes for the future.

Each individual will react in their own way depending on personality, coping skills and relationships within the family and other family members and friends might experience one or more emotions at different times from each other.

Suddenly the world you knew has changed. Time is needed to take in what is happening and to work through the many emotions being felt.

Some people may not want to talk about what is happening, while others would like to talk through everything.

Reach out to MNDSA (08) 8234 8448 for a hard copy (free for members) or you can download a copy via this link:

<https://view.mndnsw.org.au/mnd-aware-aspects/page/1>

MNDSA Thank You



Adelaide Appeals Committee

Thank you so much to the Adelaide Appeals Committee who made MNDSA their charity of choice for their annual Thanksgiving Wreath Party that was held in November 2022 at Jarmers Kitchen. Pictured above are some of the committee members, with MNDSA CEO Karen Percival in the middle holding a cheque with an amazing \$20,000 to donate to our community.

Thank you, ladies of the Adelaide Appeals Committee, it is because of people like you that we can continue to do what we do.



Team Not D'Feated

A big thank you to the effervescent "Team Not D'Feated", which tirelessly raise funds and awareness to support MNDSA. Their last annual fete, held in October 2022, raised over \$7000 of much-appreciated funds to assist South Australians living with MND. Thank you Team Not D'Feated, from our hearts to yours.



Drouin Littlehampton Open Garden Weekend

Thank you to Sue and Jim, the owners of "Drouin", for choosing MNDSA as the charity of choice, from funds raised from opening their beautiful garden to the public in early November. \$11,500 was raised, and is already making a difference to people living with MND. Special thanks too, to our wonderful volunteers who helped out on both days - by all accounts, it was a pleasure to help out in such exquisite settings.



Walkerville Social Climbers

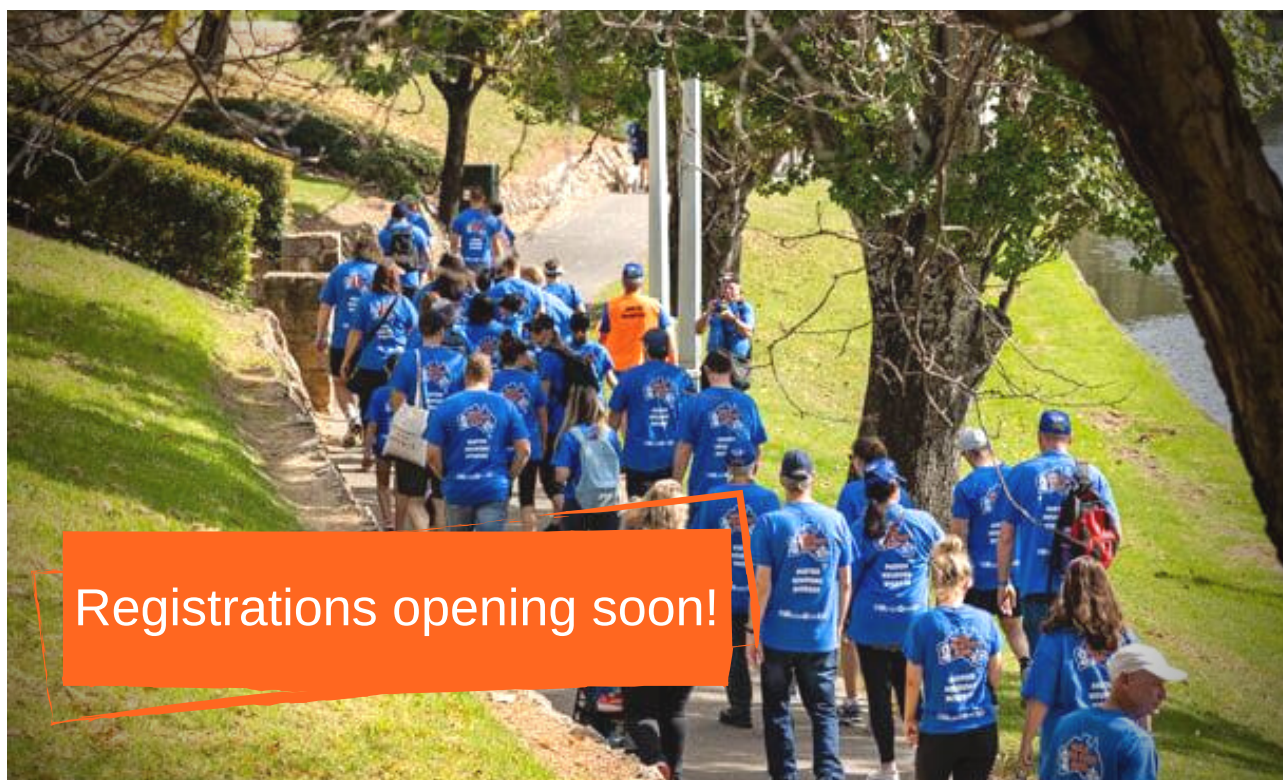
Each year the Walkerville Social Climbers bike riding group do a charity race up Norton Summit (first Saturday of December). Each person donates \$25 to compete, with all proceeds going to MNDSA. The race is called the Ray Kopp Challenge named after Ray who passed away from MND approximately 10 years ago. They have been doing this event and donating for over 10 plus years. Ray's wife Mel and their daughter Lucy always come out each year and help out with the race.

A little action often spurs a lot of momentum Noah Scalin

Upcoming Events



The Walk to D'Feet MND is the most loved event on the MNDSA calendar. It symbolises the hope that one day we will defeat this dreadful disease, whilst it serves as a memorial to those we have lost. We're aiming to welcome 1000 participants this year, so rally your troops and join our tribe!



Registrations opening soon!

The event starts at 9am with a delicious choice of food and beverage stalls. A large seating area is set up for your convenience or you can sit under the shady canopy of trees in the grassed areas.

Live entertainment and children's activities will be actively engaged and as our community arrive, they can spend time catching up with each other, and relish the ambience of this most special event with the backdrop of the beautiful flora and fauna that Pinky Flat is so well known for.

Special guest speakers commence from 10am, and the walkers, led by the Pipe and Drums of the Royal Caledonian Society start the walk at 11am.

On your return take advantage of more live entertainment over lunch with new-found friends, and your team.

When: Sunday 30 April 2023

Where: Pinky Flat, War Memorial Drive North Adelaide

Time: Entry from 9am
Guest speakers from 10am
Walk Commences at 11am
Event finishes at 2pm



Keep an eye on our website and social media for the registration opening date.

We're not meant to walk tough journeys alone. Support our amazing MND community on Sunday 30 April, 2023

Upcoming Events & Fundraising

MNDSA is looking forward to bringing exciting events to our community in 2023

MNDSA 2023 Event Calendar

Walk to D'Feet MND

30 April 2023

Larapinta Trekkers Trivia Night

28 July 2023

The Larapinta Trek

16-21 August 2023

Day of Hope and Remembrance

22 September 2023

MNDSA Gala Dinner

November 2023

MNDSA Christmas at The Zoo

10 December 2023



MNDSA is currently welcoming
Corporate Partners
for tailored
Event Sponsorships

Please contact us at:
fundraising@mndsa.org.au
or call 08 8234 8448

1st Prize Toyota Kluger Hybrid GX RRP \$59,551	Early Bird Prize! 	2nd Prize Toyota C-HR GR Sport Hybrid RRP \$42,306
	3rd Prize Kooco 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

People's Choice Community Lottery

We are once again a participating charity in the People's 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. If you want to purchase tickets and support MNDSA, you can just scan the QR Code, and you are on your way! Good Luck!



Research Update

State of Play webinars in 2023



Due to its' continued success, MND Australia's state-of-Play webinar series will continue into 2023, allowing the MND community to hear directly from funded researchers. The range of topics covered in 2022 was broad, from an overview of why there is so much diversity in disease presentation and progression between patients, to hearing about the MiNDAUS registry, advances in brain-computer interfaces, through to finding out about what goes wrong with nerve cells. To find out more about upcoming webinars, keep an eye on this link:

www.mndaaustralia.org.au/research/research-news-updates/state-of-play

Clinical Trials in Adelaide

Further to our feature article with Associate Professor David Schultz, he and his local research team are working on two clinical trials in Adelaide. The first of which is called the Lighthouse II trial which is investigating the potential benefit of an antiretroviral therapy. This trial has commenced.

COURAGE-ALS, is the second trial, an international multi-centre trial which is exploring the potential benefit of Reldesemtiv, a molecule being investigated for the improvement in muscle function. This study is taking place in 16 countries across Australia, North America and Europe. The screening process is currently underway for potential South Australian trial participants.

A potential new treatment for people living with MND.



In the December 2022 edition of their research publication 'Advance' MNDRA shared an exciting development in the treatment of MND.

The therapy RELYVRIO™, developed by Amylyx, has been approved in both the USA and Canada.

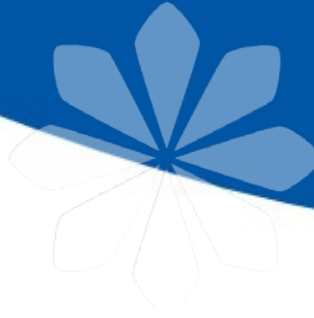
The US FDA were happy that RELYVRIO showed a sufficient slowing of the loss of physical function in people living with MND from a phase 2 clinical trial.

This announcement is welcome news for people living with MND and MND Australia is reaching out to Amylyx to commence discussions about options for bringing the treatment to Australia.

Continue reading:



Larapinta Trek 2023



Following the hugely successful Flinders Ranges Trek in 2022, MNDSA, in conjunction with Inspired Adventures, are trekking the Larapinta Trail 16-21 August 2023.

The Larapinta Trail is regarded as one of Australia's premier walking tracks. From the old Alice Springs Telegraph Station to the peak of Mount Sonder, the trail stretches 223 kilometres along the backbone of the West MacDonnell Ranges.

As part of this 6-day adventure, you can stand on ancient escarpments and gaze out upon the ochre-coloured landscapes of Central Australia. You can follow Aboriginal Dreaming tracks and trek beside one of the world's oldest river systems.

By day, you would experience the diversity of desert habitats and learn the unique history of Australia's Indigenous peoples. At night, you can fall asleep to the sounds of native wildlife under a blanket of stars.

- Experience Central Australia and explore the mountains, valleys, rivers and desert landscapes of the Red Centre
- Uncover the history of Australia's traditional owners and gain a deeper understanding of Indigenous culture
- Ascend Mount Sonder, one of the Northern Territory's highest peaks



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

Challenge yourself to tackle the Australian Outback with this bucket list experience, all in the name of supporting people living with MND.



Larapinta Trek 2023



Registrations

The registration process for this adventure is simple. You can scan the QR Code below, or go to: <https://inspiredadventures.com.au/event/mndsa-larapinta-2023/>

Once you have registered, you will be paired with a member of the Inspired Adventures fundraising team who will be there to support and inspire you every step of the way. The support they provide is personally suited to your time availability, level of experience and network and give you as much assistance as you need, to reach your fundraising goal.

Fast Facts

Dates



16-21 August 2023
6 day trip, 4 day challenge

Fundraising Target



\$3,500

Accommodation



Twin share in 4-star hotel
comfortable swag camping

Difficulty



3/5

"The varying physical capabilities of the group were readily accepted and supported by the entire group" A/Prof. David Schultz, Head of Neurology, Flinders Medical Centre.





Larapinta Trek 2023

The MNDSA Trekkers Trivia Night is held to assist registered trekkers with achieving their fundraising goals.

MNDSA TREKKERS TRIVIA NIGHT

- Friday 28th July
- 6.30pm-10.30pm
- Thebarton Community Centre, Torrensville
- Supporting our 2023 Larapinta Trail Trekkers
- Pizza (pre-order)
- BYO nibbles / Drinks for Sale
- Raffle, Live & Silent Auctions
- Special Guests
- Wine Wall
- much, much more.....

mnd South Australia



Giving

Monthly donations are the most reliable source of income - they mean we can worry less about raising funds and focus more on delivering care and support.

Living Legacies

The John Hepworth Memorial Fund

Following the passing of Archbishop John Hepworth in December 2021 from MND, the church building that was his place of work was sold, and the funds raised were placed into the John Hepworth Memorial Trust Fund. An impressive donation of \$123,000 was pledged to MNDSA.

Church members Dulcie, and Laurel (pic below left with MNDSA CEO Karen Percival), were instrumental in MNDSA being selected as one of the beneficiaries so that we can continue our vital support services. It was lovely to meet with them recently and show our appreciation for this thoughtful and generous gift.



Regular Giving

If you feel strongly about the need for a cure, we would love you to consider signing up to our monthly giving program as a Regular Giver.

Every day, every hour there is a grateful client and family who have experienced support the MNDSA way. Individual, meaningful, compassionate, practical. This level of care is at the heart of MNDSA. You or someone you know may have experienced this support. All proceeds go towards the provision of MND care.

If you would like more information on regular giving go to: <https://www.mnlsa.org.au/ways-to-give/monthly-giving/> or scan the QR code.





Corporate Sponsors

Vicki Shearer, Executive Officer of the SAPN Employee Foundation has been a long term supporter of MNDSA.

In this edition of our MND news, we are pleased to shine a spotlight on one of our most active corporate supporters, the SA Power Networks Employee Foundation - driven by Vicki Shearer.

We asked Vicki for a brief Q&A overview of why she and her team choose to support MNDSA and how they are helping to make a difference in our MND community.

What do you enjoy most about your role as Executive Officer of SA Power Networks Employee Foundation?

For me, the positive interactions with other people and having the opportunity to see people at their best is very rewarding.

SAPN Employee Foundation supports many worthy charities in South Australia, why do you choose to support MNDSA?

Our relationship with MNDSA is a close one, more like a friendship. We have several staff members who have sadly had family members with MND and a couple of our staff too. We love the hands-on, practical help that MNDSA give and the way we can see the impact of our support.

Are you joining the MNDSA's 2023 Walk to D'Feet MND event on Sunday 30 April, and if so, what are you most looking forward to?

We have done the Walk to D'Feet MND for 7 years in a row, we won't be dropping out now! We love the venue at Pinky Flat and the bringing together of people for a shared vision is very rewarding.

You've generously donated \$20,000 to MNDSA in 2022 to support the Life Stories project. What do you hope this project achieves?

I hope it brings some peace of mind to those who will no longer be with us that their story will live on and to their family and friends who get to keep the story, some comfort in their time of grief. Also, its amazing what you can find out about someone you thought you knew really well!

A few key facts about the SA Power Networks Employee Foundation:

The Employee Foundation was established in 2006 and to date has **donated more than \$4 million to the South Australian community.**

The Foundation enables their employees, their families and friends to make a positive contribution to the lives of people in the SA community through:

- volunteering
- fundraising
- donations of money, goods and services.

We sincerely thank Vicki Shearer and Staff at the SAPN Employee Foundation for their generous, ongoing support of MNDSA. It is truly appreciated.



Vicki Shearer (L) and Kate Burgun (R)

MND Client Services



MND Education

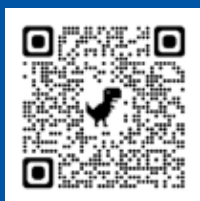
Our first 'Introduction to MND SA' Session for 2023 will be held on Wednesday 8th February from 6.00pm - 7.30pm at Thebarton Community Centre.

Our MND SA Client Services Team members Denise Schoder and Leanne Shane will share information about MND and MND SA's services, in a comfortable and informal environment.

Light refreshments will be available, and we encourage partners, carers and family members to come along. For catering purposes, please register via the link or QR Code below.

We will be hosting these sessions every 2nd month. Please keep an eye on our events page for further information:

<https://my.mndsa.org.au/events/51/copy-of-an-introduction-to-mnd-session->



MNDEquip

MND SA has a great range of equipment and assistive technology to support communication, mobility, respiration, bathroom and bedroom safety. When referred by a health practitioner, items may be subsidised to people with MND.

MND SA Warehouse Officer Peter Smith (above) is always happy to assist you with our delivery and collection service. For more information visit the QR code below.

Items include:

- Beds, lifters and slings
- Shower chairs, toilet raisers and commodes
- Pressure care cushions and mattresses
- Walkers and mobility devices
- Manual and powered wheelchairs
- Scooters
- Communication and other access technologies
- Respiratory devices (suction and cough assist)



MND SOUTH AUSTRALIA

66 Hughes Street,

Mile End, SA 5031

Mon - Fri 9am - 5pm

Phone: (08) 8234 8448

Freecall: 1800 777 175



admin@mndsa.org.au



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www.linkedin.com/company/mnd-south-australia

We acknowledge Aboriginal and Torres Strait Islander peoples as the Traditional Custodians of the lands in which we live, work, and learn. We recognise and respect the enduring relationship they have with their lands and waters, and we pay our respects to Elders past, present, and emerging.