

# MNDnews

The newsletter of the Motor Neurone Disease Association of South Australia



**Walk to D'Feet MND 2022**

**YOU WILL NEVER WALK ALONE**



# MESSAGE FROM THE CEO



## A Landmark year...

After living with COVID-19 for more than two years, we certainly made up for lost time at The Walk To D'Feet MND 2022. We were thrilled to see over 700 people from our community, past and present, walking side by side on Sunday 1 May. For photographs and memories just see page 4.

At the walk the SA government confirmed a funding commitment to MNDSA of \$2.4 million dollars over four years, commencing July 2022.

The SA Minister for Health, Chris Picton stated that this was in recognition of the advocacy that the Association has undertaken, highlighting the inequity of funding for our older clients, who are ineligible for the National Disability Insurance Scheme and the critical role that MNDSA plays in supporting them.

We would like to thank all the members of our community who have worked with us over the last few years to advocate and inform our politicians in South Australia, ensuring we have been heard.

The funding will enable us to expand our services as detailed on Page 11.

Whilst MNDSA will still need to fundraise to deliver its services, it is wonderful for the first time in 35 years to have our state government recognise the plight of our MND community by supporting MNDSA's services, and together we will continue to advocate to the Federal Government for the systemic changes that are needed.

Recruitment is already underway and you can see a few new staff announcements on page 3.

On the topic of staff, it is with pride that I thank our amazing team for their professionalism, passion and dedication to our community. This is not only evident in how they work together but also by the amount of positive feedback we have been receiving from members of our community.

National MND week is from June 19 - 25 with Global MND Awareness day on June 21st, the same day as Winter Solstice. We have a number of well known Adelaide iconic buildings and bridges lighting up for MND Week, see page 6 for more information

As one of the successful Palliative Care Grant recipients through The Department of Health and Wellbeing, we introduce "Talking Grief". A new service offering that will provide a loss, grief and bereavement support program to help people impacted by a diagnosis of MND. This initiative will unfold during the second half of 2022 and for further details see page 9.

We are also expanding our volunteer programs and are calling out for people who have anywhere from a few hours to a few days a week to join us - see page 9 for further details.

One thing for sure, 2022/23 is going to be a busy year for MNDSA - but we are all excited for the improvements in supports it will deliver to our community.

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

**Karen Percival**  
CEO

# MNDSA Staff

MNDSA are delighted to announce two new team members



## Introducing Denise Schoder

Denise joined MNDSA following a long career as a registered nurse working in the Aged Care community sector. Our Association caught Denise's attention due to the recent death of a family member from MND as she witnessed first hand the impact this disease can have on the person and their family. Denise's particular focus at MNDSA will be supporting our older clients who continue to struggle with navigating the Aged Care service system.

## Introducing Lisa Walsh

Lisa is a registered nurse with experience working in the community as well as with NDIS participants. Lisa has a lived experience of family members impacted by disability and will be ensuring our clients who qualify for the NDIS continue to get the support and services they need to remain involved in their community.




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# MNDSA Thank you

MNDSA would like to thank the many people in our community who have kindly donated items they no longer need, for our equipment pool.

The lifter below left, and electric wheel-chair were donated recently and are examples of the amazing equipment we receive, so that we can help others who may not be able to fund these items themselves.

If you have equipment that you would like to donate to MNDSA, please contact our Warehouse Officer Peter Smith on e: [psmith@mndsa.org.au](mailto:psmith@mndsa.org.au) or 08 8234 8448 to discuss in more detail.





# MNDSA Reflections

## The 2022 Walk to D'Feet MND

The 2022 Walk to D'Feet MND was a true celebration of the "collective beating heart" of our amazing MNDSA Community.

Not since the pandemic started has this event enjoyed such a fantastic attendance and spirit of camaraderie. And, we were not the only ones to hand out the kudos!

Newly elected SA Health Minister Chris Picton, who joined us on the day to confirm the Labor Party's funding pledge to MNDSA, thoroughly enjoyed meeting members of our community. (Further information on this pledge is in the CEO report on page 2)

This event made it on several news channels both locally and nationally, raising awareness of the issue of funding for clients not eligible for the NDIS as we continue to advocate for our community.

To the 75 volunteers that helped us behind the scenes and on the day - thank you from our hearts to yours. It's because of people like you, that we can do what we do.

Finally to our wheelers, walkers and fundraisers - It is you who truly bring this event alive and we applaud everyone of you!

We look forward to seeing you next year!!!



### A BIG MNDSA thanks to the following superstars who made this day possible.

- Adelaide City Council
- Adelaide Lions
- Alan Hickey
- Andy J Sound
- BankSA
- Beverley Storage King
- Blackwood Ukulele Group
- Derek McClure
- Groove Bros Soul Sister
- Kytons Bakery
- MNDSA Volunteers
- Norwood Foodland
- Rosa Matto
- Rotary Club of Blackwood
- Slapes Sausages
- Solar Eggs
- Springfresh salads
- The Pipes & Drums of the Royal Caledonian Society of SA Inc
- Thomas Foods
- University of Adelaide
- YMCA SA

# MNDSA

## Thank you

MND NEWS WINTER 2022



### Saxon's Ironman Fundraiser

#### Why did I choose to donate to MNDSA?

In 2010 my mum was diagnosed with MND. Two years later in 2012 she passed away. Growing up she was a single mum and a huge role model to me. Her resilience, sense of humour, charisma and loving nature had a unique way of influencing others.

As with all other families that experience MND first hand, it was very difficult to see someone you love slowly deteriorate.

The support that MNDSA and other community support agencies provided us over these difficult times was fantastic, helping mum to remain in her own home and easing the burden on family care. May 2022 will be 10 years since mum passed away and I thought it would be a good opportunity to give something back to those who helped us.

I was participating in my first Half Ironman event in Melbourne and decided to link up a small fundraising campaign. Everyone's generosity was outstanding, raising \$1,557.54 for MNDSA.



### #Never Give Up Concert

The Campbelltown City Band, in conjunction with special guests St Ignatius Stage Band and Brilliant Brass entertained us recently with a delightful musical filled Sunday afternoon fundraiser for MNDSA.

It was our privilege to be entertained by such talented musicians, especially our Warehouse Manager Peter Smith as Conductor.



### Peoples Choice Lottery

Thank you to every one who purchased a ticket/tickets in this lottery. The final tally was \$5,292 and we appreciate your support.



### SA Power Networks Employee Foundation

A huge thanks to Vicki Shearer and the Foundation for your generous donation of \$15,000 towards our Walk to D'Feet MND.

The Foundation has supported us with donations totaling \$63,760 over the years and it is great to have them on board as supporters of our soon to be launched "Life Stories" Program.

They are also helping us with the promotion of our 2022 Tax Appeal on the SAPN building on Anzac Highway. If you are stopped at the traffic lights - glance up to see our appeal on display!!



Scan the QR Code to make a donation.





# Upcoming Events

## MND Awareness Week 19 to 25 June 2022

This year MND Awareness Week is being recognised throughout Australia in the third week of June. MNDSA, together with MND Australia and our National network, undertake a variety of media, fundraising and awareness activities to raise community recognition and understanding of the disease.

MNDSA undertakes a lot of advocacy and activities to help raise awareness of the condition and we encourage all members of the MND Community to participate whenever they can.

MND week is a time when people living with MND, those who have lost someone to MND, carers, researchers, staff and volunteers can unite and reflect on their journey.

This year MNDSA will be lighting up some key landmarks in Adelaide in our signature "Cornflower Blue" for MND Awareness week, with the support of:

- SAHMRI
- Parliament House
- Adelaide Oval
- The Glass Footbridge
- Adelaide Convention Centre
- Adelaide Entertainment Centre



**MND Global Awareness Day is on June 21 which is winter solstice.** This represents our hope for a turning point in the search for causes, better care, treatments and ultimately a cure. Over 420,000 people worldwide live with ALS/MND – a disease that affects people in every country of the globe. It does not discriminate on the basis of ethnicity, socioeconomic status or region. One day, through research, we hope to live in a world free from MND.

## Drink Tea for MND is a tea-riffic fun and easy way to raise much needed funds for MNDSA.

Whether it's high tea, chai tea or black tea it is as simple as ABC... Pick a date, time and place and start inviting. You will be supporting the search for a cure, and better support for those living with MND.



<https://www.drinkteaformnd.org/>

# Personal Story

## Brenda Bowey

### **I'm not going to allow MND to define who I am as a person**

After almost 2 years of symptoms, starting with an unexplained limp, and a number of falls, which had me going to an ENT for answers about my balance, throwing covid in there for good measure and 4 months of many tests including Cat scans, x-rays, MRI's, Spinal tap and muscle conduction tests, on Friday the 27th of August 2021 my husband Ian, and I, were given the gut-wrenching news that I did indeed have MND.

It was one of the first questions I asked my neurologist at our initial appointment "could it be MND" after a friend of mine who had succumbed to the disease a few years earlier showed some of the same symptoms. I was told that was "way down the list of possibilities". But it was always in the back of my mind.

We had sold our business in Whyalla and moved to the lovely Barossa in September 2019, to live in the house we had bought a few years earlier to retire to and be closer to friends and family.

After working in my cafes for 18 odd years I looked forward to semi retiring and for a complete sea change at 58 years old and went and got my forklift licence. I secured a position at Maggie Beers as a store person, hacking around on a forklift loading and unloading trucks and packing orders of arguably some of the finest food in Australia for supermarkets. It was a job I absolutely loved, but a position I couldn't continue with as my symptoms grew worse.

In December 2021 after it was becoming harder and harder to work safely, I decided to "retire" and enjoy the things that makes me truly happy in the time I have left. But I'm not going down without a bloody good fight.

The literature about everyone's journey being their own, are all different. The time of "27 months" gets bandied around. I intend to take my inspiration from the man, Neil Daniher, who has really shone the spotlight on this shit of a thing



we call the "Beast". I plan on having at least another 5 to 6 years, if the gods allow, to see and do the things I want, to spend every chance I can with those I love the most.

I am fortunate to have a slowly progressing disease. It has only affected my leg and hand now, which makes walking difficult, and I drop like a tree if I'm not mindful about where I put my feet thanks to my non-existent balance. So, my days are now spent, if not catching up for a coffee or a little "day drinking" with my friends in my beautiful garden (and when I get too tired out there), sitting in my favourite chair, stitching or crocheting treasures for my family and friends to have as a memento to remember me.

I have been well and truly blessed with the people I have in my life, who are here to help me on this journey: my husband Ian, my two sons Andrew and Pete and my rock of a friend Cindy, and what can sometimes seem like a small army of family and friends, or as they are known "Brenda's gang". We know it's going to be an enormous challenge, but we will go through it together.

The support we have all had from the team at MNDSA has also helped us navigate some of the processes that without them would have been difficult and knowing that they are there to chat at any time to offer the support we need has been invaluable.

**We will never give up**

*Brenda Bowey*  
*June 2022*



# LIVING BETTER

## Neck Collars

by Georgia Mackie



A neck collar, also known as a neck brace or a cervical collar, is a useful tool for people with Motor Neurone Disease (MND) experiencing neck weakness and difficulty holding up their head.

By supporting a person's neck, a neck collar can assist with providing increased comfort, decreasing neck and head pain, and users can get on with daily activities.

### When might neck collars be recommended by your Clinician?

- For those finding it increasingly difficult to hold the weight of the head;
- For those experiencing neck and head pain;
- To provide support during car trips, especially those on windy or bumpy roads; and/or
- To provide support during mealtimes to facilitate swallowing of solids and liquids.

MNDSA have a variety of collars available that can be fitted and tailored to suit a client. Collars currently available include soft neck, headmaster, Aspen Vista, Head Up and Philadelphia.

It is important to note that one collar might not meet all needs and multiple collars may be prescribed to accommodate multiple activities. It may be necessary to trial several different collars to find the most suitable fit. Regular reviews are essential, as a change in collar type may be necessary if a person's neck strength changes.

### Soft Neck Collar

A soft neck collar is as it sounds! It is made from soft foam covered with a stocking-like material. This collar comes in sizes XS-L and has a Velcro fastening making it easily adjustable to provide maximum comfort and independence.

It provides moderate support through the front, sides and back of the neck, making it ideal for early stages of mild neck weakness and during car trips and transfers.

### Headmaster Collar

This collar provides support to the head and neck, while maintaining a low profile look which can be worn underneath clothing. It comes in sizes S, M and L and can be bent into shape with assistance to suit each client. Headmaster collars may need a bit of trial and error and frequent readjustment to bend the collar into a position that provides individualised support and comfort and comes with chin pads to provide additional comfort to the chin. These can be replaced as needed and additional pads can be purchased to be positioned at the end of the chest support for extra comfort.

### Aspen Vista Collar

This collar limits neck rotation and sideways bending of the neck, providing support for moderate to severe neck weakness. The height of the collar and tightness around the neck are adjustable and it has a wide opening at the front for ventilation and works to reduce the sense of being restricted.

### Head Up Collar

The head up collar was developed in the UK and designed specifically for people with MND and designed to keep the head from dropping. Made of flexible materials, it can be worn while eating and drinking. The collar consists of a soft 'snood' which can be customised with either medium or firm struts to provide individualised support. The collar can be adjusted if a person's neck strength changes.

### Philadelphia Collar

These collars are made from a thin molded foam with plastic supports to provide support to the back and neck and reduce sideways bending and rotation of the neck. This can be useful when travelling in a vehicle. This collar is easily adjustable with a Velcro strap around the lower neck and comes in sizes S, M and L. It has a large opening at the front of the collar for ventilation purposes.

People with MND have individual supports rather than a 'one size fits all'. For more information on neck collars please contact MND SA on (08) 8234 8448 to arrange to chat to one of our clinicians and see if a neck collar might be a suitable support for you.



# LIVING BETTER

## NEW Loss, Grief and Bereavement Support Program

**Australian research has shown the impact of loss, grief and bereavement on people affected by a diagnosis of motor neurone disease (MND). Carers are particularly impacted by a loved one losing function and needing increasing help with activities of daily living.**

MNDSA are thrilled that the Department of Health and Wellbeing have chosen our Association to be recipients of another palliative care grant in 2022-23. Our application, to fund a new project called "Talking Grief", was chosen from many applications to build capacity in the state's palliative care sector.

The project will unfold during the second half of 2022 and aims to develop a sustainable state-wide loss, grief, and bereavement support program to help people impacted by a diagnosis of motor neurone disease (MND). We will partner with local and regional palliative care service teams and other organisations with expertise in this area.

Volunteers will be trained to build skills and knowledge to provide loss, grief & bereavement support. They will be able to gently explore common grief reactions and identify and implement effective strategies to support individuals. Training will ensure volunteers can identify when to refer to professional grief counsellors and how to care for themselves whilst supporting others. Training will also be provided to MNDSA staff to ensure awareness and appropriate referrals.

Once operational, the program will provide weekly support opportunities and include one to one interactions, groups, telephone or video calls.

Benefits will be to engage clients and their carers and help mitigate prolonged grief that can be caused by the traumatic nature of MND. This will help MNDSA to identify people who may be at risk of experiencing the prolonged psychological distress that can lead to major depression requiring specialised therapy.



**We would love to hear from anyone who may be interested in volunteering to become a part of this exciting initiative. If you would like more information about this or any of our other opportunities, please email: [volunteer@mndsa.org.au](mailto:volunteer@mndsa.org.au) or call us on 08 8234 8448**

# MND RESEARCH

Vassilios Karnaros, PHD Candidate at the Flinders Health and Medicine Research Institute at Flinders University.



My research career began as a 2020 Honours student after completion of my Bachelor of Medical Sciences at Flinders University. I started my PhD focusing on identifying and measuring molecules useful for measuring MND progression in clinical trials. I hope to continue my research focusing on MND with Assoc Prof Mary-Louise Rogers, my Supervisor and a Board Member of MNDSA.

Our laboratory is renowned for identifying molecules in the urine of people with MND and to identify if treatments in clinical trials are working. We can then identify if potential treatments are reducing or halting the progress of MND and are called "progression biomarkers". They show the rate of disease progression and the focus of my research.

Although the cause of MND is still unknown, we now know that MND involves nerve cells and other physiological processes, eg inflammation in the nervous system. Immune dysfunction and neuroinflammation also assist in characterising MND, resulting in multiple actions on immune system cells and nerve cells. Anti-inflammatory and pro-inflammatory molecules are secreted by cells of the immune system during MND, providing biomarkers of the health of nerve cells as the disease progresses.

At the Australian and New Zealand MND Conference in April 2022, I presented our work describing a small molecule called neopterin as a biomarker of pro-inflammation in MND.

It is released by the immune system when it undergoes inflammation and becomes damaged. When released into circulation, neopterin is filtered by the kidney's and measurable in urine, using targeted clinical tests.

As joint first author with Dr Stephanie Shephard, we recently published an article in the European Journal of Neurology\* showing urinary neopterin is

a biomarker of disease progression and an important biomarker of pro-inflammation in MND.\* This study used a traditional method for neopterin measurement called an ELISA, however, the measurement of urinary neopterin has since been refined.

I am now focusing on developing a high-performance liquid-chromatography and mass spectrometry method to measure neopterin. A highly sensitive, specific method of measuring neopterin in MND urine and may help clinical trials developing potential anti-inflammatory therapeutics for people with MND.

I won an award for best in clinical and patient focus presentation at the Australian and New Zealand MND conference for my poster "Refining the Measurement of Urinary Neopterin: A Biomarker of MND presenting a high precision mass spectrometry method as a better way to identify and measure neopterin for people with MND." I would like to sincerely thank MNDSA for providing me with support to attend this conference.

Moving forward, I will use mass spectrometry as a refined method to measure neopterin in MND urine, validating this method for future clinical trials for drugs that target inflammation and immune dysfunction. Together, the benefits of ongoing biomarker discovery and validation are driving clinical trials towards the development of tailored therapeutics, such that we can work together to reach a better conclusion to beat MND.

1. Shephard SR, Karnaros V, Benyamin B, Schultz DW, Dubowsky M, Wu J, Chataway T, Malaspina A, Benatar M, Rogers M-L. Urinary neopterin: A novel biomarker of disease progression in amyotrophic lateral sclerosis. Eur J Neurol 2022;29:990-999.



# MNDSA

## Expanding our Client Services



**The recent announcement of funding by the SA Government to support people living with MND who are not eligible for the NDIS, has given MNDSA an opportunity to expand some of our key services and supports.**

### Information, Advice, Case Management and Support Service

Funding will enable additional support coordination and case management for older people with MND. We will continue to offer our electronic and written resources as well as expanding education for clients, carers and the community. Our Client Service team liaises closely with the MND Clinic at Flinders Medical Centre to ensure that we are part of a strong multi-disciplinary care team. [As outlined on Page 9 we will also be introducing a grief, loss and bereavement service that will have trained volunteers available to provide additional support to our community.](#)

We will continue to provide our Coordination of Support service to all clients able to access the NDIS. The service includes support for clients to access the NDIS, as well as advice to ensure that their first NDIS support plan suits their needs. Once a plan is in place, our Support Coordinators will help participants liaise with providers, get supports in place as well as monitoring and reviewing their plan.

### Allied Health Services

MNDSA has a small team of occupational therapists (OTs) and allied health assistants (AHA) who work exclusively with our clients to support them with mobility, getting in and out of bed or a chair, providing communication support 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 AHAs can follow up with clients and their carers to address specific training they may require.

MNDSA is a registered NDIS provider and clients, who have a funded NDIS support plan, can let their support coordinator know to choose MNDSA to provide their specialist OT services. Our team are experts in assisting clients to navigate the NDIS for their support needs and in understanding the trajectory and future needs of our community.

We are expanding our allied health services to include a speech and communication service for the first time. A speech pathologist and a dedicated AHA will support people with complex communication needs by providing advice, strategies, training and access to appropriate low tech and high tech equipment.

### MNDEquip

This service is able to provide equipment and assistive technology to all clients. The service supplies rental equipment and our staff will deliver, install and collect items as well as provide information about its correct use.

MNDEquip is subsidised by MNDSA for clients. Most MNDEquip assistive technology items are rented to MND clients, with single use items purchased by clients. Rental fees include any maintenance and reasonable repairs that may be required during use. Clients are invoiced each month for costs associated with their equipment for the previous month.

If you have any needs please contact us for assistance:

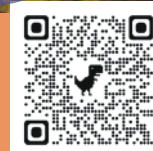
✉ [supportservices@mndsa.org.au](mailto:supportservices@mndsa.org.au)

☎ 08 8234 8448

# MNDSA 2022 Flinders Trek

*Are you up  
for  
the challenge?*

Join the MNDSA Flinders Ranges Trek 2022 and share the adventure with members of our community who share a common bond - to support those impacted by Motor Neurone Disease.



Every step you take on the trek will help provide the best possible care and support for people living with MND in South Australia. As part of this incredible adventure, over five days, you will experience the history and majesty of one of the world's oldest, unchanged landscapes. You will explore some of the most visually stunning scenery in Australia, immersed in the dramatic

beauty of high ochre ridges, deep gorges and water-courses lined with river red gums. You will share stories around the camp fire with your fellow Trekkers - all to support MND South Australia's life-changing services and fund research into the cause, cure and treatment of MND. Just call MNDSA 08 8234 8448 or register your interest by scanning the QR code or via:  
<https://my.mndsa.org.au/events/16/trek-flinders-ranges>

## Meet two of our awesome Trekkers

### Associate Professor David Schultz, Head of Neurology and the MND Clinic, Flinders Medical Centre

MNDSA have a close relationship with the MND Clinic - so it is wonderful to have David on board showing the clinics support for the work of MNDSA and our community. David has been involved in the MND Clinic for over 10 years and is an experienced clinical trials physician, and is well published in many areas within Neurology including Motor Neurone Disease.

We appreciate David taking time out to give his support.

### MNDSA Chair, Scott Penhall

Scott cared for his wife Anna, who was diagnosed with Motor Neurone Disease in 2018 in her late forties, sadly passing away late in 2020. He is a family man with 3 children and during Anna's Journey, both Scott and Anna were huge supporters of the work of MNDSA, undertaking significant fundraising and helping us raise awareness of supports that are needed for our community.

Now Scott's mission is to make a difference by helping drive our strategy to help others as part of the MNDSA Board.

Scott enjoys keeping active and will be setting the pace for us all at the Trek!!



## MNDSA

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Mon - Fri 9am - 5pm

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