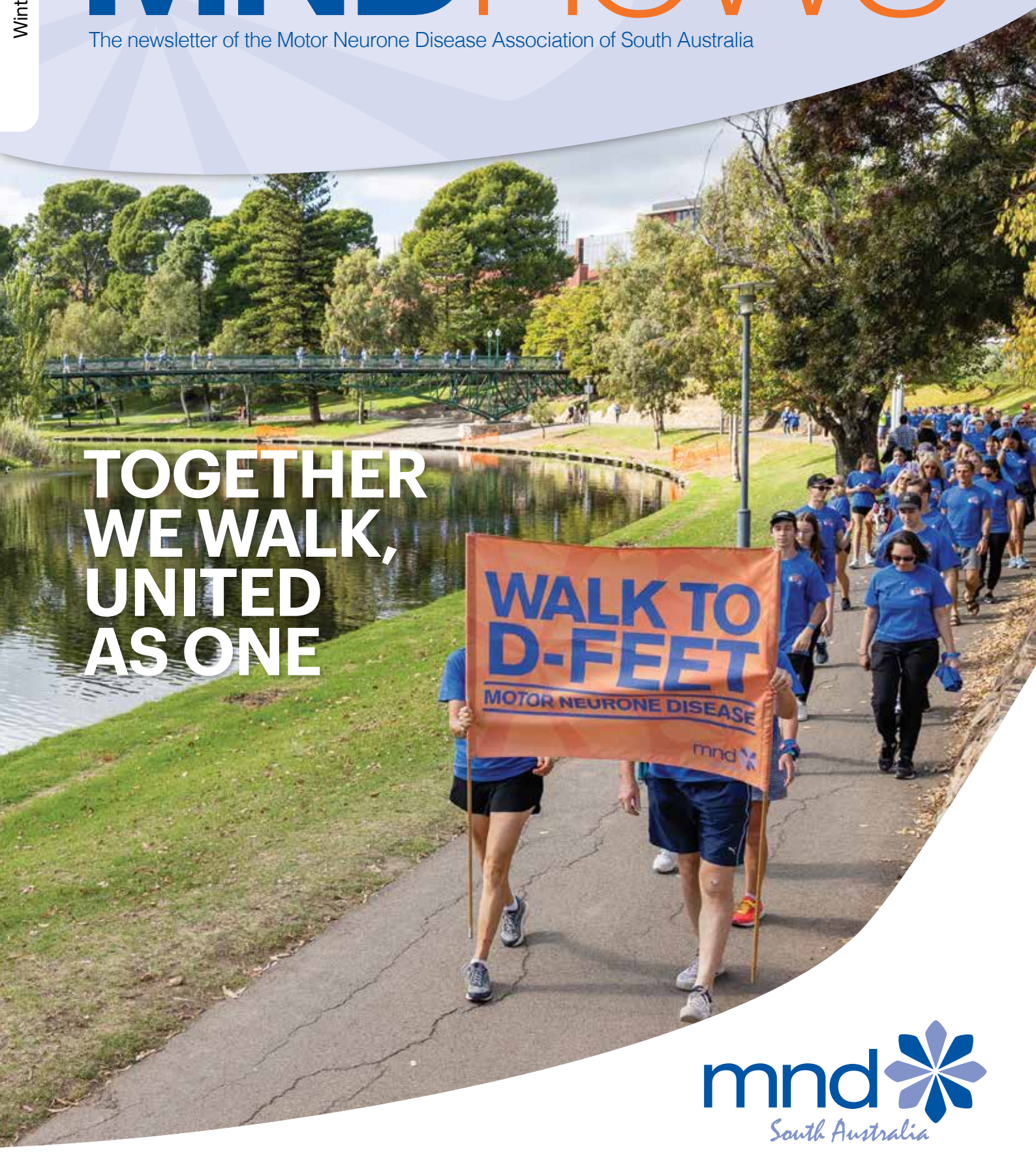
Winter 2021

MNDnews

The newsletter of the Motor Neurone Disease Association of South Australia



TOGETHER WE WALK, UNITED AS ONE

mnd South Australia

Until there's a cure, there's care

MESSAGE FROM THE CEO

Right: Karen Percival, CEO

Over the last 12 months, MND SA has been transitioning to expand the supports that we can offer to the South Australian MND community. One of the ways in which we have been able to do this is to enter into partnerships with other organisations with the same ethos.

The upgrade in our offices and facilities could not have happened without the generous support of the Masonic Charities Trust. As announced at the Walk to D'Feet MND, they awarded us an amazing $228,000 grant which allowed us to expand to our new offices, secure a custom vehicle to deliver critical equipment and devices to people living with MND, and upgrade IT for online patient records, asset management, telehealth, e-learning, online fundraising, and e-commerce. Grants such as these ensure that fundraising dollars which we work so hard to achieve go back into funding staff to support our over 65's community.

MND SA has always supported research, but a significant donation in memory of Dr Julie Lawrence (the first female plastic surgeon in South Australia, who passed away from MND in 2019), has enabled us to co-fund an MND Research Fellow through a partnership with Flinders Foundation and the Flinders Medical Centre Clinician's Special Purpose Fund.

The fellowship is supporting Dr Kate Johnson in caring for people living with MND and their families, and progressing research at South Australia's sole MND clinic. As a result, research and clinical trials exploring new treatments for MND are underway right here in South Australia at Flinders Medical Centre.

A few months ago, we had Carers SA present at our "You, Me & MND" information session. Working in partnership with them, this month MND SA presented to their staff about MND, the needs of carers, and how the funding they have available can best be allocated to support our community. Support from them is available regardless of whether the person with MND has funding from another source, and we are advocating to ensure our community get fast track supports wherever possible.

We have also been working with the National network of MND Associations to ensure that our concerns are being heard regarding the proposed implementation of Independent Assessments in relation to the NDIS, and we are currently trying to get appointments with Senators in this regard.

Please rest assured that we are working hard to improve the supports available to our entire community.

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

Karen Percival ,
CEO

Left: David Booker, the new Grand Master of the Freemasons of South Australia and the Northern Territory

Above: Julie's husband Steve Meldrum, Dr Kate Johnson and Julie's brother Graham Ragless.

MND SOUTH AUSTRALIA SAYS **THANK YOU**

The MND SA Walk to D'Feet 2021

Pinky Flat was vibrant with the sea of blue t-shirts on Sunday 2nd May for the 13th Annual Walk to D'Feet MND, raising an essential $75,000 to continue our services over the coming year. Our 700 plus Walking Warriors and their four-legged friends symbolised unity, strength, courage, and pride, at this most loved of events on the MND SA Calendar.

The Blackwood Ukulele Group set the morning rocking with their colourful stage presence. The egg and bacon rolls were a smash hit for brekkie, as was the beautifully brewed coffee by DeJa Brew. MC Chris Dittmar hit the stage highlighting all on offer and introducing special guests. MND SA CEO Karen Percival spoke with passion about the year that was, and the positive path ahead for MND SA and our Community, announcing a wonderful grant of $228,000 from Masonic Charities Trust to fund our expansion to new premises and upgrades in our resources. Grand Master Mr David Booker, from The Freemasons of South Australia and Northern Territory, spoke about the grant, and officially opened the Walk to D'Feet. Then came the beautiful and emotive sound of the bagpipes and drums as the Caledonian Pipe and Drum Band led the walkers on their way. The stunning backdrop of the River Torrens created a magnificent life-long memory for the walkers and spectators. The Adelaide Lions Club were ready with the sausage sizzle and donuts as the walkers returned for a well-deserved snack, and the Moon Dance Band were there to entertain the troops until early afternoon.

This event could simply not happen without our huge crew of volunteers and the generous organisations that support us. Special thanks to all of our staff, board members, family members, friends of MND SA, Adelaide University students, and Bank SA staff, who gave their time to ensure a memorable day for all.

It is always wonderful to see so many members of our MND community, past and present, who come and join us for this annual event. We hope you are looking forward to supporting our community again next year!

A big MND SA thanks to the following who made this day possible:

- Masonic Charities Trust
- Bank SA Staff Volunteers
- Lions Club of the City of Adelaide Inc.
- Chris Dittmar, MC
- Derrick McClure - Event Photographer
- Caledonian Pipe and Drum Band
- Audio Pod Party & Event Hire
- AJS Lighting Sound Events
- Chilly Billy
- City of Adelaide Council
- YMCA
- St Johns
- Storage King Beverley
- Solar Eggs
- Holco (Thomas Foods)
- Blackwood Ukulele Group
- The Moon Dance Band
- Deja Brew

MND SOUTH AUSTRALIA SAYS **THANK YOU**

Staff Focus

We are very fortunate to have two new staff members joining us at MND SA. Meet the new additions to our team!

LYN WATSON
Support Coordinator

Lyn has a background in health education, having previously worked as State Manager for Nursing Australia. She has also worked in Aged Care, Palliative Care and Community Health for the over 65's.

Lyn strongly believes in patient advocacy and person-centred care where a holistic approach is an impetus to providing the best possible service.

EVE YEH
Administration Officer

Having worked as an Accounts Officer for the past 3 years, Eve jumped at the opportunity to join MND SA.

Volunteers

Our MND SA volunteers play a critical part in the MND SA journey, and we would like to thank all of them for their "hands-on" support - we simply could not do what we do without you.

Again, special thanks to the Walk to D'Feet volunteers who were a huge help behind the scenes leading up to the event, and from sunrise on the day. Your energy and enthusiasm are endless and with hands on heart, we thank you.

As our business grows, so does the need for more volunteers who can assist MND SA in office administration, awareness campaigns, fundraising events, and support for clients throughout South Australia.

If you would like more information on becoming an MND SA Volunteer, visit http://my.mndsa.org.au/volunteer, scan the QR code below or call us on 08 8234 8448 for more information.

LIVING BETTER

Communication and MND

Communication is an integral part of our daily lives. Communication involves more than communicating by speech and using our voice.

Social communication is how we interact and engage with the people in our lives and the broader community. If you are experiencing communication changes due to MND, it is helpful to know that there are lots of strategies and supports available.

Here are some practical tips to help you communicate:

- **Be mindful of the environment** – reduce noise, face your communication partner, allow yourself extra time.
- **Consider using technology to support you to communicate a different way** – this may be using a text to speech app (on mobile phone or tablet) or using a communication software with an eye gaze device.
- **Have other ways of communicating beyond talking** – using a pen/paper, pointing to a photo on a board, using gesture, or responding to yes/no questions.
- **Conserve your energy to support your communication abilities.** Some examples include – resting before social events to enable you to communicate more easily; or connect with your friends/family through text messages rather than phone calls if you find this easier.
- **Pictures are worth a thousand words!** Use photos to enhance your social communication. Take photos of activities that you do throughout the day. Send the photos to a family member, friend or community group. Ask that they send you photos back. See how this has a positive impact on your social interaction!
- **Use social media (e.g. WhatsApp, Facebook Messenger) to create private groups.** Private groups are a great way to keep in touch with family, friends or other community groups you are involved in (e.g. cricket club, Rotary club, etc.). It allows you to easily send messages and/or photos so that you can stay socially engaged with the people in your life.
- **Spend some time in nature.** Nature has been shown to positively contribute to wellbeing and provides an opportunity to slow down, reflect, and create a 'mindful moment'. You may feel inspired to take a photo of something that you find beautiful or that catches your eye. Share this photo with the people in your life. You may like to create an Instagram page, public or private Facebook group, or send it around to your family or friends.
- **Send a daily or weekly email around to the people in your life.** Like a newsletter, include a summary of things that you find funny, quotes, photos, or anything! Let your personality shine through.

A speech pathologist can support you to communicate as effectively as possible with the people in your life. We will listen to what is important to you, who are the meaningful people in your life, and assist you to come up with ways to communicate and stay socially connected with the people who matter to you. An occupational therapist may also be involved to explore new ways of accessing your communication equipment or technology if your hand/arm function is changing.

Kaela Gomizel
Speech Pathologist,
Calvary Health Care Bethlehem

PERSONAL STORY

Keeping Our Eyes on the Stars

by William Pridmore (MChD) Royal Hobart Hospital Hobart, Tasmania, Australia

Originally published in RRNMF Neuromuscular Journal 2021;2(1):8-9

The real problem is time.

She was finding it a bit harder to lift her foot. It was irritating, and she found she was limping. She made passing comments to her husband and son of some "electrical shocks" in her legs, which she thought were due to anxiety. That combination worried me, but I didn't tell her. It couldn't be.

A "foot drop" is a symptom in which the muscles that lift the toes towards the head lose this ability. There are many causes for such a presentation, and determining the culprit is challenging. Things didn't improve, and so she underwent a series of investigations. The neurologists who administered the nerve conduction studies were kind, but she noticed they exchanged serious looks throughout the test. She'd have to wait for the full report.

The full report was not good.

When the diagnosis of motor neurone disease is made in a family member, the world changes. It darkens around the edges, and loses some of its lustre. One can deal with the impending physical challenges as they arise. But it's the time that gets you. For most patients, lifespan is between two and five years from diagnosis. Nothing stops the march towards oblivion. We know how this story goes.

Massachusetts native Dr Stanley Appel is one of the rock stars of this condition. At 87, he valiantly continues the research and clinical work he began as a young doctor. He calls MND "nice guys' disease", based on his observations that MND patients are typically driven, empathetic, generous, and otherwise healthy. Scientific studies, comparing patients with a healthy control population, confirm his notion [1]. MND patients are card-carrying nice guys – that's part of the injustice.

Research into MND has been frustratingly slow since the condition was first described by French neurologist Jean-Martin Charcot in the 1860s. Degeneration and death of motor neurones (nerve cells that control muscle movement) in the brain and spinal cord leads to progressive paralysis of voluntary muscles. The causes have remained elusive, and the biological processes that go astray are highly complex.

Most cases occur at random, but a minority run in families. When the first known genetic contributor was identified in the 1990s, it inspired the first animal model of MND, using laboratory mice. Such mouse models of MND have provided important insights about the injury of motor neurones, and have offered a useful way to test for the beneficial effects of various drugs. Unfortunately, these models have failed to bear much fruit. Contributing factors include poor experiment design, incompatibilities between mouse and human disease, and inadequate understanding to allow for informed therapeutic proposals [2].

My name is Will, and I was thrust into the MND community after my mother, Mary, was diagnosed in June last year. I am a doctor by trade and wrote this article to share the impact of this diagnosis on a family, as well as to provide some context and optimism regarding the hunt for treatments. We are grateful for the support provided by MND Tasmania as we navigate this condition.

But something is shifting.

Decades of work by devoted researchers have discovered much of what leads to MND. There is more optimism than ever before. Slowly but steadily, scientists are developing a working knowledge of motor neurone death. In the same way MND insidiously takes over a body, research is progressively uncovering its secrets – and will eventually banish it. Several drugs and treatments show early promise.

2020 saw the launch of three MND "platform trials": one in the UK, one in the USA, and one in Europe. Regularly used in cancer research, platform trials allow several drug candidates to be compared to a single placebo (fake drug) group at the same time. Contrasted with traditional clinical trials, platform trials may cut testing time in half, and expense by a third. The arrangement also means fewer patients who participate in trials will receive placebo. For a platform trial to be viable, there must be enough medications in development. For a drug company to develop a medication, it must know enough about a particular condition to identify a likely therapeutic target. Drug company interest in MND has increased out of sight over the last five years [3].

University of Michigan linguist John M. Lawler offers the term "railroad time". It describes how, when science and technology is sufficiently advanced, it is natural for several people to make a discovery concurrently. Railroads were invented when it was "time for the railroads". I guess it is "railroad time" for MND platform trials.

Key discoveries hint that laboratory tests to reliably diagnose and monitor nerve damage may soon be available [4]. "Biomarkers" like these are desperately lacking. Implementation of such tests would revolutionise drug development, as researchers could tell quite quickly whether their medication was having an effect. The code is being cracked. You can hear the pins falling into place.

For now, we have learned to celebrate the small things, and seek joy. A new orthotic has stabilised her walking. Her arms are still strong – suddenly her love for kayaking is amplified. Her painting studio, always a special place, is now her salvation.

It is clear that MND is increasing in prevalence [5]. Despite its dramatic effects, the condition remains relatively underfunded. The Fight MND Foundation, championed by Australian Football League great Neale Daniher, has brought needed attention to our plight – and other excellent organisations around the world continue to raise funds.

More is needed, and needed quickly. Two Australians are diagnosed with, and die from, MND every day. The battle against this condition has felt like Sisyphus eternally pushing his boulder up a hill, only for it to roll back down when it nears the top. But now there is a difference. With renewed awareness and financial support, we may actually, finally, reach the summit.

And hopefully Mum will be standing with us, waving the flag of victory.

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3. van Eijk RPA, Genge A. The rise of innovative clinical trial designs: what's in it for amyotrophic lateral sclerosis? Amyotroph Lateral Scler Frontotemporal Degener 2020;21(1-2):3-4. DOI: 10.1080/21678421.2019.1681455

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MND RESEARCH

Unravelling the genetic origins of MND

While the understanding and awareness of MND continue to grow, the underlying causes remain largely unknown. To date, the only proven cause of MND is gene mutations that are essentially typos in the letters of our DNA sequence.

Clinicians first described MND in the mid-1800s and, soon after, a large family from Vermont was identified in which multiple individuals were affected by MND. This family provided the first clue that there is a hereditary or genetic component of MND, and we now know that approximately 10% of all individuals affected by MND have a similar family history, and are classified as having familial MND. Though clinicians gradually expanded the understanding of the clinical presentation of MND, the first major breakthroughs in understanding the biology of MND did not come until the 1990s. It took 113 years from the identification of the Vermont family, to finally solving their cause of MND as a genetic mutation within the SOD1 gene, representing the very first MND gene discovery in 1993. In 2006, the principal component of protein clumps apparent in MND was found to be a protein called TDP-43. This led to genetic investigations of the gene encoding this protein, TARDBP, which in 2008 revealed that mutations within this gene do, in fact, cause MND. These discoveries demonstrated the crucial interplay of the genetics and biology of MND, and researchers have continued to use genetics to inform the further study of the biological mechanisms involved in MND.

In 2009, a powerful DNA sequencing technology called next-generation sequencing was developed, which can produce enough genetic data to provide a complete genomic profile of an individual within just a few days. This technology has facilitated an explosion in the number of MND genes discovered over the past decade, both by our Australian research team and by geneticists across the world. However, these known MND genes still only explain two-thirds of families afflicted with MND, and ~7% of individuals affected by the non-familial or sporadic form of MND, leaving up to 90% of all people affected by MND without any identified genetic predisposition to MND. However, it has been shown that ~50% of the risk for any form of MND, whether familial or sporadic, is attributable to inherited factors. Therefore, the identity of many of the genetic changes contributing to the cause of MND remains to be discovered.

An important theory has been postulated by our collaborators in the UK stating that six individual events or "hits" need to accumulate within an individual to trigger the onset of MND. These hits could be genetic risk factors or environmental exposures we are yet to identify. Supporting this theory, our research team has recently shown that among people affected by MND, those who carry multiple MND mutations and/or genetic risk factors develop MND earlier in life than those without any such genetic alterations.

Our research team has collected DNA samples from over 600 Australians affected by MND and have utilised next-generation sequencing to determine the complete genetic profiles of each of these individuals. This is an incredibly powerful resource containing a huge amount of genetic information. In addition to analysing families affected by MND using approaches similar to those used to identify SOD1 as the first MND gene, we are also looking for MND genetic risk factors, which are genetic alterations that, while present in the general population, are more common among people affected by MND. However, as these genetic risk factors only contribute to small levels of MND risk, they are very difficult to identify, and very large numbers of study participants are required for their discovery. Our team is involved in a large international consortium called Project MinE, which collects genetic profiles from individuals affected by MND from across the world. So far, over 10,00 genetic profiles have been collected for analysis in a coordinated effort to discover novel genetic risk factors for MND.

MND genes are used for diagnostic testing and facilitate early diagnosis of MND, which allows clinicians to provide efficient management strategies with a view to delaying progression. This affords family members opportunities to utilise genetic testing if they so wish, under the guidance of skilled genetic counsellors. This includes pre-symptomatic testing to understand their own risk of developing MND, and/or the ability to utilise preimplantation genetic diagnosis together with IVF to prevent future generations from inheriting MND-causing mutations. MND genes and the proteins they encode are also prime targets for developing effective therapeutic interventions to treat MND. While not yet a reality, we are working towards using genetic profiling to tailor treatment strategies for each individual. Together, these benefits of MND gene discoveries are driving us toward personalised medicine approaches to treating MND within individuals and families in the hope that we can ultimately outsmart and beat the beast that is MND.

Emily McCann, PhD
Beryl Bayley MND Postdoctoral Research Fellow
Centre for Motor Neuron Disease Research,
Macquarie University

UPCOMING EVENTS

Glitz and Glamour Gala Dinner 2021

We are thrilled to announce that bookings for this event are now open!

It is time to dust off your glitzy attire, practice your dance moves and join us for a wonderful evening of food, wine, entertainment, music, and laughter to help raise funds to support South Australians living with motor neurone disease.

Enjoy valuable time with family and friends whilst being entertained by Matt Tarrant who has been called Australia's Best and Most Popular Magician. His awards and sold-out tours speak for themselves. Performing as a mentalist, Matt combines these psychological skills with insane magic abilities and creates a fun, incredible, and jaw-dropping stage show involving plenty of audience participation.

When: Friday 6th August 2021 7:00 pm – 1:00 am

Where: Festival Function Centre, Findon

Dress Code: Dress to Impress

Ticket price includes: 3-course meal, 5-hour drinks package, live music, auctions, and entertainment.

Early Bird Tickets: $160 per ticket or $1550 per table of 10. Early bird closes on June 30th.

Ticket Prices 1st July onwards: $175 per ticket or $1700 for table of 10.

Book online at: https://my.mndsa.org.au/gala or scan the QR code below.

Live and silent auction items – can you help us?

Calling on our community, family, and friends to help show your support.

We are accepting donations of prizes and experiences to suit all ages, to list in our live and silent auctions on the night.

We like to offer as many diverse experiences and items as possible and ask, if you can contribute or know a business or special contact who can help, that you call us on 08 8234 8448.

Bunnings Edwardstown Sausage Sizzles

Sausage Sizzles are a great way for us to meet and greet the public and have some fun with our volunteers, teammates, and families, whilst fundraising for our cause.

We require five (5) people to participate in three (3) hour shifts (8.00 am to 11.00 am; 10.45 am to 1.45 pm; and 1.30 pm to 4.30 pm) on the following dates:

- Sunday 11th July 2021
- Saturday 16th October 2021
- Sunday 5th December 2021

Please give us a call if you can help and would like to join in the fun on 08 8234 8448.

You, Me and MND

Join us for these informative and social sessions that are designed for MND clients, their carers, family, and friends.

Each session is held at our premises in Mile End from 11:00am - 1:00pm.

Following the educational aspect of each session, light refreshments will be served and there will be the opportunity to mix and mingle with other guests and MND SA staff.

For details of upcoming sessions and to book, please visit https://my.mndsa.org.au/events, scan the QR code below or call MND SA on 08 8234 8448.

GIVING

Dawn's Story – Tax Appeal 2021

Dawn is a fiercely strong woman with a wicked sense of humour. She has also been living with MND for just over two years.

MND is terminal, there is no remission and the average time from diagnosis to death is 2.5 years.

On top of being diagnosed with a disease that has no known cause, treatment or cure, Dawn is over 65 years old which means that she does not qualify for the National Disability Insurance Scheme (NDIS) and the huge amount of support and equipment that it would provide. Instead, Dawn can only access the Aged Care system which is ill-equipped to support anyone living with a degenerative disease like MND.

This means that, instead of potentially being funded for up to 50 hours of care a week, and being able to access all the necessary assistive equipment, the best the family can hope for is a Level 4 Aged Care package or the equivalent of 10 hours of care per week, which they are still waiting for.

Dawn and her family rely on us to help provide the best possible care and support, and we rely on your generosity.

Dawn and her family wanted us to share their story as they know how important it is to raise awareness and funds for other families going through MND now and in the future.

If you are in a position to contribute, your gift can provide much-needed support for South Australians living with MND, just like Dawn.

Visit https://my.mndsa.org.au/tax or scan the QR code below to watch Dawn's Story and to donate to MND South Australia.

Please dig deep so that those who hear the fateful words "You have motor neurone disease" can still enjoy life and remain independent, safe, and engaged with their community for as long as possible.

MND SA CLIENT SERVICES

People living with MND, their carers and families, may access a range of services and supports from MNDSA including:

- **Basic counselling, support and care coordination for clients and families, including referral to other services.**
- **Information and advice about MND.**
- **Occupational therapy assessment and support.**
- **Provision of equipment and assistive technology.**

MNDEquip – Access to equipment for all MND SA Clients

The provision of equipment and assistive technology is also known as MNDEquip. MNDEquip has consolidated all equipment into our warehouse, located at the rear of our headquarters at 66 Hughes Street, Mile End. The new warehouse layout includes a 'come and try area', where clients, their family and carers can make an appointment and trial our range of equipment items to assist people living with MND.

We have a great range of items to support communication, mobility, respiration, bathroom, and bedroom safety. Items available include:

- Beds and bedroom equipment
- Lifters and slings
- Shower chairs, toilet raisers and commodes
- Pressure care cushions and mattresses
- Walkers and mobility devices
- Manual and powered wheelchairs
- Scooters
- Respiratory devices (suction and cough assist)

Who can use MNDEquip?

All MND SA clients may use MNDEquip services if unable to access equipment through an alternative funding source, or while waiting for that service to respond (includes waiting to access the NDIS).

MND SA clients who are accessing funding via the NDIS may still choose to use MNDEquip services while trialling an item, or while waiting for a permanent item from an alternative supplier.

Most items are provided to people with MND on a loan basis, and at the end of this period, are collected for refurbishment and loan to others in need. All equipment is thoroughly checked and cleaned as per strict cleaning protocols by MND SA before rental. Should you require an item that is customised or otherwise not available from MND SA, your clinician can work with you to provide information about alternative supply options.

Costs

MNDEquip is subsidised by MND SA 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.

mnd South Australia

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