## MNDnews

The newsletter of the Motor Neurone Disease Association of South Australia



## HELP FOR OVER 65s WITH MND

Labor Party commits to part funding MNDSA with \$2.4m over 4 years in State Election pledge



## MESSAGE FROM THE CEO



Since its inception, MNDSA has advocated enthusiastically on behalf of people living with MND, largely to encourage the South Australian Government to provide funding support to help ensure the continuity of our broad range of services. We firmly believe that people with MND deserve strong and committed support from society and that our ability to provide these services should not be contingent on raffles and sausage sizzles.

I am delighted to announce that our many years of advocacy have finally paid off. On 24 February 2022, then Leader of the Opposition Peter Malinauskas MP and Shadow Health Minister Chris Picton MP visited MNDSA to announce a funding support commitment that would come into effect should the Australian Labor Party win the 2022 SA State Election. Following the landslide result we are now looking forward to making this funding commitment a reality as it represents \$2.4 million funding over 4 years to support the provision of our Disability Equipment Service and will also allow MNDSA to employ staff to support the members of our community who are ineligible for NDIS and are on waiting lists for Aged Care packages.

In this edition of our newsletter we share details of some new MNDSA staff and board members along with updates from some of our committed board members. On Page 10 Assoc Prof Mary-Louise Rogers shares details of her ground breaking MND research. On page 4, Stephen Pisani is supporting us with an innovative fundraising concept whilst also creating a memorial for the late Anna Penhall who lost her battle with MND in December 2020 and who was wife of our current Chairman, Scott Penhall.

Despite the future injection of funds from the SA Government, we wouldn't be able to offer the client services and programs we do without the generous support of our community with MND and their networks. This year we are looking to introduce new fundraising concepts and events to hopefully spread awareness of MND with a wider audience whilst raising much needed funds to support our programs. 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 get in touch.

After living with COVID-19 for more than two years, we are hoping to make this year's Walk to D'Feet MND our biggest yet.

Nobody should be walking their MND journey alone. So, we hope you can gather your tribe and come and meet all the staff and board and other members of our community as we get together on May 1.

Until there's a cure, people with MND need care right now. Walk alongside us and help us to deliver it.

Karen Percival, CEO



# NEW MNDSA Board Members and Staff

MNDSA are delighted to announce two new appointments to casual vacancies on the MNDSA Board, and two new staff members.



### **Introducing Andrew Danson**

Andrew is a Graduate of the Australian Institute of Company Directors with experience in the retail, food and beverage industry. Having lost his father to MND in 2020, he understands the difference our association makes to the lives of people impacted by MND and is looking forward to contributing to MNDSA's service to the community.

### **Introducing Andrew Holmes**

Having grown up in Adelaide, Andrew brings a wealth of experience with a background in PR, Media, Marketing and Communications, working for national and state sporting bodies and starting his own consultancy business, Aitch Communications. He is excited to continue supporting the MND community, having previously worked for three years as the Marketing & Communications Manager for FightMND.



## Thank you for volunteering to help MNDSA make a difference, helping our community

## **MNDSA** New staff

#### **Introducing Kesey Hean - Occupational Therapist**

Kesey joined MNDSA in 2022 after working previously with Brain Injury SA and MS Society of SA/NT. She has years of experience working with clients needing complex equipment and home modifications and has a real understanding about how to get the best result for our clients using the NDIS and Aged Care systems.

She has years of experience working with clients needing complex equipment and home modifications and Kesey looks forward to making a differing in the daily lives of our community.





## **Introducing Angela Burnett - Allied Health Assistant**

Angela joined MNDSA to complement her studies in Occupational Therapy at Flinders University. The community that MNDSA represents and provides services to, caught her attention as she has always had a passion for neurology and wants to explore more in this field. Angela will always bring along a smile and is looking forward to meeting our clients and supporting all on their MND journey.

#### Welcome to the MNDSA Team

## MNDSA **NEWS**

## An exciting new initiative

We are pleased to announce an exciting new initiative that we are involved in that pays tribute to Anna Penhall's legacy and also demonstrates innovation in fundraising to ensure MND patient needs are met.

One of our board members, Stephen Pisani, runs a successful accounting firm and has created a new property development company which is managing a 23 unit townhouse development in Kurralta Park, In what we believe is a first in SA, the Development company named S&S Property Developments have agreed to auction one of their properties and donate the profits from the sale to MNDSA.

The development has attracted the support of suppliers and tradies who are either donating all or part of their respective services to maximise the donation to MNDSA.

Not only that, but the laneway that will run down the middle of the development will be formally named Anna's Lane in memory of Anna Penhall.

Whilst S&S Property Developments are a profitable business they have a strong desire to be a charitable organisation and give back to those in need. It is an extremely generous gesture on the part of S&S Property Developments and we are truly grateful for their generous support.



## PERSONAL STORY

Peter and Lyn have accepted his diagnosis and are making the most of life.

The 7th of August 2020 was a day I'll never forget. I was with my wife, Lyn, when we received the devastating news, I had MND. This came after many blood tests, scans, MRIs, visits to a rheumatologist, and a muscle biopsy over a period of 10 months. During the process of elimination, my GP had warned me that MND was a real possibility, so when we did receive the diagnosis, it wasn't a complete shock.

Time was of the essence. Immediately we bought a collapsible mobile scooter called a 'Luggie' and began booking holidays. In October 2020 we flew from Adelaide to Darwin and returned platinum class on The Ghan, then spent December and January in Tasmania with our daughters who both live there. A week in February was spent on the river aboard the Murray Princess. We had a three-week road trip in April, through Victoria, New South Wales and Canberra visiting friends and relatives along the way. We enjoyed several more trips to Hobart before our travelling days ground to a halt in August last year.

My symptoms began in my legs – feeling like lead and not wanting to work. Since then, it's been a slow decline where now my arm strength, fine motor skills and general mobility have gone. I'm completely reliant on Lyn to do everything for me.

I now have wheelchairs, lifters and a BiPAP breathing machine amongst other things. I am fortunate to still have my speech and can still chew and swallow – although I did have a PEG insertion 12 months ago for when that's no longer possible.

As you see, we've accepted our fate and are making the most of life. Our family and network of friends have been both positive and supportive. Living in a small country town provides the opportunity to 'walk' down the street and chat to my many friends along the way - something we try to do on a daily basis.



Peter and Lyn on the Murray Princess and with family L-R Pierre, Lucy, Bryce and Kate and Grandson Alexander

A motorised wheelchair hired through MNDSA makes this a possibility. MNDSA have also provided us with many aids, giving us the ability to return and change items as necessary and are just a phone call away if we have any problems or queries.

There are not enough words to describe the support and help that Lyn provides. She is my physical carer, my emotional support, my confidante, best friend, and love of my life. The enormity of the challenges facing her are almost unimaginable, yet she gets on and does what's needed. This challenging journey is as hard on her as it is on me, and I cannot and will not ever be able to thank her enough.

I've had many career changes throughout my life – firstly joining the Navy in 1972, where I met Lyn, married in 1976 and had two beautiful daughters – Kate and Lucy. On discharge from the Navy, I did an adult apprenticeship in cabinetmaking, owned a café and restaurant, worked in the building industry, then finished my working life as a picture framer and a funeral director.

The support of my loving family is what motivates me to stay positive and live life to the fullest.

Besides... watching our 4-year-old grandson grow, is reason enough to keep going.

## **Upcoming Events**

We invite you to join us on May 1 for our largest community event on the MNDSA annual calendar - The Walk to D'Feet MND 2022



Sunday 1st May, 2022 Pinky Flat, North Adelaide Event 9am to 2pm Walk set off 11am

You can register for the Walk to D'Feet MND via https://walktodfeetmndsa.com.au/ or by scanning the QR Code.



Come and walk alongside us to make this the largest walk for Motor Neurone Disease in South Australia yet. Gather family, friends and colleagues and come join us as we Walk to D'Feet MND. We look forward to a wonderful community event where people impacted by MND and those around them can come together and show their support.

This upbeat and inspiring event is in its 14th year and is a chance for everyone to gather in solidarity and hope for a cure for MND. The easy 4.5km walk is wheelchair, pram, dog, scooter and bike friendly.

Your support matters. MNDSA is the only dedicated organisation that is here to support South Australians impacted by MND. The walk helps to raise funds for much needed support, equipment, consultations, practical services and emotional support for our community.

Nobody is meant to walk the tough MND Journey alone. We can defeat MND...but we can't do it without you. Still have questions visit our FAQ: https://my.mndsa.org.au/news/6/faq-for-the-walk-to-dfeet-mnd-2022



## INSPIRED



## <u> 16 - 21 September 2022</u>

Interested to know more: Register for the Flinders Trek via scanning the QR code or https://my.mndsa.org.au/events/16/trekflinders-ranges



## Why join us?

Come and experience the majesty of one of the world's oldest, unchanged landscapes. You will explore visually stunning scenery, immersed in the dramatic beauty of high ochre ridges, deep gorges and watercourses lined with river red gums. Better still, you will share this adventure with people with the common thread of "MND". Lifelong friendships are made from such adventures, and in many cases the first trek is never the last.

#### **The Personal Training Challenge**

The trek on average includes 4 - 6 hours of trekking a day, and the fitter you are, the more you will enjoy it. You will be given a training schedule and support.

#### The Fundraising Challenge to raise \$3000 (or more) for MNDSA.

You will be given fundraising ideas and support to achieve this goal. It is amazing how quickly the dollars add up and the tremendous sense of achievement when you reach it.

## **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 "Cornflower Blue" with the support of Parliament House, Adelaide Oval, the Glass Footbridge, Exhibition Centre for MND Awareness Week.



## Campbelltown City Band Presents "Never Give Up" Sunday 29 May - 2pm

An afternoon of live music from some of South Australia's best and brightest musicians, raising funds and awareness for the work that MNDSA does, state-wide.

Featuring the Campbelltown City Band led by our very own Warehouse Officer, Peter Smith, with special guests St Ignatius College Stage Band led by Stephen Millar, and Brilliant Brass led by Bruce Raymond OAM.

Where: St Ignatius College

2 Manresa Court Athelstone

Prices: Adults \$15 Concession \$10 U18 free

Tickets available at the door or online

100% of funds raised go to MNDSA, to support the vital work they do to assist people with MND state-wide.

#### Blue Cornflower Day Friday 24 June 2022

Blue Cornflower day is an opportunity to raise awareness and funds for the hundreds of people impacted by MND in South Australia every year.

The blue cornflower is the symbol of hope for MND around the world because of its fragile appearance but hardy nature. Like the cornflower people living with MND show remarkable strength in coping with this devastating disease.

Blue Cornflower Day is on the Friday of MND Awareness Week and is the perfect time to hold a blue themed event.

Just email: fundraising @mndsa.org.au or call MNDSA on 08 8234 8448 for more information and ideas.....



# LIVING BETTER MINDAUS PARTNERSHIP

## **New MND Registry**

Many of you have taken part in the Australian Motor Neurone Disease Registry (AMNDR) and this is a precious resource that may be useful for future generations.

The AMNDR has now been replaced and updated as part of a National Health and Medical Research Council funded project called the MiNDAUS (pronounced MindOZ) Partnership. This partnership consists of a broad Australia wide membership including Clinicians, Clinics, Researchers, and support organisations such as MND Australia, MNDSA, other state organisations and FightMND.

The Project entitled "Motor Neurone Disease: Patient centred care for a progressive neurological disease – evidence driven policy" has three core themes:

- Empowering patients and their carers through the
  development of patient and carer registries. The
  Patient Registry, as well as recording personal details
  and preferences, allows the patient and carer to
  monitor the progression of the condition in an objective
  and qualitative way and to report this to their MND
  service coordinator and clinic, thus allowing timely and
  relevant support in and efficient manner. Such selfmanagement has been shown to be a critical
  component of patient and carer wellbeing. The Clinical
  Registry provides a record more medically related data,
  including genetic data arising from patients, who give
  consent, to broader, more research related,
  involvement.
- Integration of Data Collection in MND involved bringing together data from the Australian MND Registry and the sporadic ALS Systems Genomics Consortium into a single platform which can be readily accessed by scientists and others under strict governance provisions. The patient and carer registry data is part of this very rich collection of information to inform research, the provision of better care, and policy.



 Integrating Evidence to Inform Policy. There are many policy improvements needed to effectively respond to the unique needs of those living with MND. This must be facts based and requires reliable data and its transformation into areas where change is most needed, the development of policy and implementation, with its translation into practice.

#### **Progress to date:**

- The Patient Registry has been developed and is currently being rolled out in several clinics with the engagement of MND associations and patients themselves. Patient and carer feedback is very positive. The Carer Registry is in the early stages of development.
- The Data Bases have been combined and the necessary governance provisions established to protect patient confidentiality, and integrity of data use. Requests are now being received from research scientists for access to this valuable source of factual patient information.
- Areas of critical policy need have been identified along with the necessary data, in order to enable changes which support improved service delivery (such as skill development of those working in MND, and telehealth), and for continued research.
- A pool of people living with MND (PLeX), along with the necessary supports, is being established to ensure grass roots input into future research and service delivery.
- The future of the MiNDAUS Partnership at the end of the current project is being explored including diverse funding sources, and a closer working relationship with MND/MNDRA.
- The MINDAUS Partnership is already recognised nationally and overseas for its achievements in a patient centred approach, and this will be promoted further.

To find out more, visit
www.mindaus.org (or scan the QR
code on the right) contact your MND
Advisor, or contact Catherine Hansen,
MiNDAUS Operations Manager at
e: catherine.hansen@deakin.edu.au
or ph: 0467 523 911



## LIVING BETTER

Staying connected.

Maintaining wellbeing in the time of social distancing.

Staying connected and engaged with friends, family and community is important, not only because it adds pleasure and meaning, but because it can also improve our quality of life and support our mental health.

We want to make sure that during this time, you have ways to stay connected to your family, friends and community, even if you can't see them in person.

#### **USING TECHNOLOGY TO CONNECT**

We are lucky to live in a digitally connected world. Here are some ways you can connect with others wherever they are:

Video calling Most smartphones and computers can make and receive video calls, so that you can see and hear the person you're talking to. Platforms such as Zoom, FaceTime or Skype allows people to stay in touch with loved ones, attend religious services, learn new skills and keep up with medical appointments.

Online groups Starting an online group where people can chat or leave messages can help you stay connected at any time. You might set up a group for your family, or your friends. Your group might discuss anything and everything, or you might have a focus, like an online book club or gardening discussion group.

Assistive Technology (AT) There are a range of assistive devices to help people. If a person's hands are weak, special keyboards or an adapted mouse can be used. Computers, smart phones and tablets can be operated via special switches and scanners. Switches can be operated by small movements of muscles. Voice amplification can help those whose voice is weak and soft but not slurred. Other devices can assist someone to communicate if their speech quality is not clear.



Augmentative and Alternative Communication (AAC) is a term used to describe communication strategies that supplement or replace speech.

#### The range of AAC include:

Simple, low tech-devices, such as writing or alphabet boards, a communication charts or lightweight devices which can have pre-recorded messages.

Apps on your phone or tablet that allow people to type out or select a message and have it spoken aloud.

Hi-tech adapted devices for those who can't use their hands, including tablets, computers and eye tracking devices with specialist software and communication apps.



#### Need help?

Whether you are a technology novice or could just use a helpful refresher, please feel free to contact us at MNDSA. One of our Allied Health Assistants can provide further information over the phone, email or even schedule a meeting to discuss further options and what Assistive Technology and other equipment may be available for hire through MNDSA.

Need more information: Call 08 8234 8448 or email supportservices@mndsa.org.au

## MND RESEARCH



Associate Professor Mary-Louise Rogers leads the MND Research program (Motor Neurone Disease and Neurotrophic Research laboratory) at Flinders University. Her research focuses on developing global strategies for monitoring MND in clinical trials and describing the fundamental biology of this disease. "Our research program is unique in using urine from people living with MND as a non-invasive biomarker source, aiming to build tools to help identify effective treatments for this devastating disease." Assoc Prof Rogers, (pictured above) is also a board member of MNDSA.

Finding an effective treatment is a priority for MND research.
However, there are some serious issues that make it difficult to design clinical trials to detect a benefit. MND is variable in rate of progress, where it starts, and if there are known familial gene involvement. Detecting a beneficial treatment is difficult because of the variable nature of the disease and because outcomes are based on a blunt approach of observing person's physical signs and symptoms.

This is where finding and characterizing measurable outcomes is critical, and where biomarkers come into the conversation. Biomarkers are measurable outcomes, usually a substance in bodily fluid or an imaging marker. Such markers can assist clinicians to group people into more homogenous groups so outcomes are more easily detected in clinical trials.

Significant progress has been made in developing generic biomarkers of nerve degeneration with two notable examples being the blood-based measurement of neurofilament light and the other, developed at Flinders University MND&NR Laboratory, the urinary

concentration of the extracellular domain of the common neurotrophin receptor.

This laboratory, led by Assoc Prof Mary-Louise Rogers at the MND & NR laboratory at the Flinders Health and Medical Research Institute, leads the world in identifying and validating urinary biomarkers for MND. We work closely with Assoc Professor David Schultz and team at the MNDSA clinic and this crosscollaboration has enabled our research to flourish. This has also involved people living with MND, willing to donate samples (urine and blood) to our projects. The MND&NR lab collaborate closely with large international groups in the USA, UK, MND researchers and clinicians across Australia.

We have also built capacity (through FightMND) in testing urine samples for p75ECD, and are beginning to validate the findings in people living with MND and have been testing samples from a small number of clinical trials (Ausbiomarker of Aust and USA). While p75ECD is a biomarker of neuro-degeneration, many other processes change in MND. One of these is the immune

system, where a protective antiinflammation environment becomes inefficient as nerves and other cells become damaged. The immune response then changes to a damaging inflammation process which contributes to worsening disease. Several markers of the pro-inflammatory response have been researched by others in spinal fluid and blood, but not many in urine.

Recently we tested a small molecule "neopterin" as a pro-inflammation biomarker. Testing urinary neopterin from people with MND found that neopterin is increased in the urine of people with MND and increases as the disease progresses, suggesting urinary neopterin may also be useful as a disease progression biomarker along with p75ECD.

The next step for our research team is to validate all of our findings in larger cohorts.

To keep up to date with latest MND Research https://www.mndaustralia.org.au/research

# MNDSA VOLUNTEERS



## **VOLUNTEER WITH US!**

MNDSA has relied on volunteers for many years. They have always stepped up whenever they have been able to, giving us their time in all manner of fundraising initiatives.

Our thanks go to our volunteers for all that they have given, despite the most challenging of times, their contributions have been crucial to the support MNDSA provides for people living with MND.

This year, we have further opportunities opening up for support. We are therefore seeking to grow our team of volunteers. In particular, we are seeking volunteers across metropolitan and regional South Australia to assist in the following areas:

- · Warehouse Duties
- Office Administration
- Event Support
- Life Stories Program
- Social Chat / Social Visiting
- ipad Buddies

All our volunteers are provided with training to prepare them for their role and ongoing support with other volunteers. For more information email: volunteer@mndsa.org.au or call us on 08 8234 8448.

Warehouse Duties assist our Warehouse Manager with equipment pick-up and deliveries, equipment maintenance and other duties.

Office Administration duties include labelling and postage of merchandise, laminating, collating packs and other similar duties.

**Event Support** at our Major Events, sausage sizzles, fundraisers and MNDSA Community events. A variety of duties available.

Life Stories Program is for good listeners who record the stories of the people that they work with and help prepare them to be printed. Being comfortable working on a computer is important for this role.

Social Visiting and Social Chat roles provide opportunities for volunteers and people living with MND to meet for regular visits or calls. Getting to know each other over discussions or exploring shared interests are key to these roles.

**Ipad Buddies** are confident iPad users who are available to provide short term support to assist new users in becoming confident using their iPad. If you would like a role that involves short term assignments this could be for you.

## **New Merchandise Alert!**

We are excited to launch the newest addition to our MNDSA Merchandise Store - "Never Give Up" socks! These vibrant crew socks are the perfect addition to jazz up any wardrobe.



Made from superior rich cotton for all-day comfort



Reinforced wear pints for longevity



Hand-linked toe for seamless comfort

They are available in both Men's and Women's sizes and are only \$10 per pair. Purchase yours today at https://my.mndsa.org.au/store/products/31/mnd-never-give-up-socks or scan the QR code on the right.

## **MNDSA CLIENT SERVICES**



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

- · Support and care co-ordination 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

#### **Allied Health Services**

MNDSA has a small team of occupational therapists (OT) and allied health assistants (AHA) who work exclusively with our clients to support them with mobility, getting in and out of bed and chairs, communication and other key activities at home and in the community.

OTs can arrange equipment options from our pool of items available for rental, as well as home modifications needed for clients to remain living in their own homes. Our 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.

For older people with MND living in the Riverland, Yorke and Barossa regions, MNDSA is funded to provide allied health and therapy services under the Commonwealth Home Support Programme (CHSP).

For other people who may be accessing or waiting for a Home Care Package, MNDSA's Allied Health team can assist where possible with OT and AHA services, along with access to our equipment services.

MNDSA are a not-for-profit organisation, and we rely on donations, bequests, grants and fundraising to continue our vital support services for people waiting to access the NDIS or Aged Care systems.

#### Just contact us for assistance:

email: supportservices@mndsa.org.au or call 08 8234 8448





#### **MNDSA**

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