

CLIENT NEWS

UNTIL THERE'S A **CURE** THERE'S **CARE**

FOR SOUTH AUSTRALIANS WITH **MOTOR NEURONE DISEASE**



FROM SUPPORT SERVICES

MND SA are determined to provide the best support for people in South Australia affected by MND. That said – it is a work in progress and small staff levels and limited funding makes it a slower process than we would prefer. There are so many different ways that you can help our shared cause. If you would like to help, give us a call!



We are excited to welcome Carlye Thompson an OT (Occupational Therapist). She will be helping MND SA clients to be assessed and gain access to life altering equipment and modifications. MND SA were fortunate to receive a grant from the QBE Foundation that enabled us to have Carlye join the team. This funding allows MND SA to have Carlye work one day per week, so her time is precious for MND SA.

MND SA has some sensational news! We have received an equipment grant of \$150,000 thanks to Cure for MND. This grant will be used exclusively on equipment to support South

Australians with MND. This enables our association to have a considerable equipment pool to support our community. Some of the items being purchased with the grant includes: electric wheelchairs, electric recliner chairs, hospital beds, assistive communication devices, shower chairs, bed sticks and other in home support aids etc.

Walk on Wheels

MND SA are partnering with Walk on Wheels South Australia, who will supply a large percentage of our new equipment, store, deliver and maintain this equipment. Walk on Wheels are a huge supporter of MND SA and the work we do for all South Australians affected by MND. If you have any queries regarding equipment and support, please do not hesitate to contact them on (08) 8293 5444.

Alternatively, you can contact Jerry, Pamela or Carlye on (08) 8234 8448.



Facebook support groups

There are several Facebook support groups out there to support those affected by MND:

MND Carers Australia support primary carers of someone with MND. The primary carer faces many challenges and often feels isolated like no one understands what they are going through. Only the primary carer is permitted to join the group and it is a safe place to discuss all issues they may face. This is a private group where you can feel supported, ask questions and vent about the difficulties you face as the primary carer of someone with MND. Group administrators hope participants will be proactive in the group and gain knowledge from others, but understand that everyone will be at different points on the MND road. Search for 'MND Carers Australia' on Facebook.

MND Angels offer participants an opportunity to share experiences and support one another. Search for 'MND Angels Australia' on Facebook.

CALS Angels is a worldwide Facebook group for all people who have lost a loved one to MND. Their collective goal is to provide a caring, understanding and supportive environment for grieving and growth after the journey of MND ends. They welcome all MND Caregivers who have lost their loved ones. Search for 'CALS Angels' on Facebook.

COMMUNITY SUPPORT PROGRAMS

You, Me and MND

Topic: MND and Research 1 2017

The February You, Me and MND Session was held on Thursday 16th February at the West Adelaide Football Club.

We had another great turn out this month. This monthly get together reaffirms what MND SA does to support those in SA affected by MND, but also to enable others to understand the supports and services available. If you haven't yet attended one of our sessions, you are most welcome to start now. Come along and to learn more about MND and possibly win a free lunch.

These monthly sessions are a way that people can socialise with others in SA who may be going through similar situations. It gives us an opportunity to update you about MND SA including fundraising events, new updates and grants etc.



MND and Research 1 2017

This month our guest speaker was Mary-Louise Rogers PhD, Senior Research Fellow and Lab Head at the Motor Neurone Disease and Neurotrophic Research Laboratory, Flinders University and Dr Roshan Vasani.

They spoke about what is MND, including the following statistics:

MND is 90% sporadic in nature, meaning no obvious or known cause of the disease. The other 10% is familial in nature, meaning it runs in the family. Mary-Louise stated the percentage of genes affected with the familial type of MND is as follows:

- C9ORF72 = 40%
- SOD1 = 20%
- TDP-43 = 5%
- FUS = 5%
- Others (up to 26 others - e.g. UBQLN2, VCP, OPTN) = combined 30%

In 2016 there had been 30 genes identified that relate to MND. Mary-Louise then asked the question – what is needed?

Biomarkers!

What is a Biomarker?

Biomarkers are needed for use in clinical trials to measure effectiveness of treatment etc. Biomarkers are a characteristic that is measured as an indicator – for example cholesterol is an indicator of heart disease. Enables monitoring of progression.

Why Biomarkers?

- Despite numerous trials no treatment has proved effective for MND
- The lack of sensitive biomarkers was identified as a major obstacle in the development of effective treatments
- At present the only validated outcome measure used in clinical trials is the Revised ALS Functional Rating Scale (0-48). This is a physical function assessment test only.
- Biomarkers may assist diagnosis in those with known mutations (e.g. SOD1). Early diagnosis can enable earlier treatment protocols, like early prescription of Riluzole medication.

What is p75 Neurotrophin Receptor?

The neurotrophin receptor p75 is released from injured neurons in Amyotrophic Lateral Sclerosis (ALS) and excreted in urine, this neurotrophin receptor p75 serves as a biomarker for MND.



What now?

They are now working towards creating a standard urinary test for p75ECD, this will be used as a progression and prognostic biomarker, helping to accelerate progress in rapid identification of new effective treatments for MND as well as exclusion of ineffective ones.

Immunogenes

They have also developed an Immunogene, used to deliver genes specifically to motor neurons, adding treatment potential. Unfortunately, they do not yet have appropriate treatment options for this method at this time.

What now?

The multinational work at the Motor Neurone Disease and Neurotrophic Research Laboratory at Flinders University continues and will hopefully provide better diagnostic and treatment outcomes in the very near future.

Our next You, Me & MND session will be held on Thursday 16th March at the West Adelaide Football Club, City Mazda Stadium, 57 Milner Road, Richmond, starting from 11am.

Catherine Hansen, a Registered Nurse working in Intensive Care, in research and administrates the BreatheMND Study at the Repatriation Hospital. She will be presenting content from the 25th International MND Symposium in Dublin December 2016.



Family Information Evening

Our first ever Family Information Evening was held on Wednesday 22nd February. Almost 30 people attended and was a very successful session providing a great deal of information to our MND community. We had a lot of positive feedback on the content and format of the evening from group participants. This session is tailored most specifically to the families and friends of those affected with MND, and we intend to hold three throughout the year. The sessions are relevant to anyone newly diagnosed or anyone with friends and family wanting to know more about MND. If you missed the session, but would like to meet with an MND Advisor to discuss MND with some members of your family etc. please do not hesitate to contact MND SA.



Photos and recording video footage

We are very excited to announce a volunteer will be recording video footage of our sessions and workshops in 2017. This will be made available to all our MND SA community. This means you don't have to miss out if you can't attend the session. A huge thank you to volunteer Anstery. Make sure you smile (or pull a face) if he is taking a photo or footage of you. Pictures and video footage taken at these events may be used on our social media and external communications, please let us know if you do not want to be included.

UPCOMING INFORMATION SESSIONS

Thursday 16 th March 11am	You, Me & MND Catherine Hansen – Trial Coordinator – Sleep Health Service RGH
Wednesday 29 th March 9am	Living Well with MND
Thursday 20 th April 11am	You, Me & MND John D'Amico - Public Trustee – Wills, Power of Attorney and Advance Care Directives
Thursday 18 th May 11am	You, Me & MND Client Led Group Discussion This is your time to get involved. This session will be open for topics and discussion pieces that interest you. If you would like to get involved and talk about a specific topic – please let us know.
Thursday 15 th June 11am	You, Me & MND Ann Buchan – Neuro-physiotherapy
Wednesday 28 th June 9am	MND & Massage 9am
Thursday 20 th July 11am	You, Me & MND - guests TBC
Wednesday 26 th July 9am	Living Well with MND
Thursday 17 th August 11am	You, Me & MND
Wednesday 23 rd August 9am	MND Aware Workshop for Health Professionals
Thursday 21 st September 11am	You, Me & MND James McLoughlin NeuroPhysio Research
Thursday 19 th October 11am	You, Me & MND - guests TBC
Thursday 16 th November 11am	You, Me & MND Dr Kerry Soon Yeah & Sr Sharon Liberali Oral Health
Wednesday 29 th November 9am	Living Well with MND
Thursday 14 th December 11am	You, Me & MND followed by the Client Xmas Lunch

Support sessions are an open informal format and provide an opportunity to:

- Gain useful information about MND and MND SA
- Network with others with MND, their Carers and families
- Socialise and share experiences
- Find out about new supports and assistive equipment
- Speak with the MND Advisors in a group setting.



Connie, MND SA's Support Services Assistant

Don't forget Connie is here Tuesday and Wednesday morning if you would like to give her a call. She will continue calling each of our clients to check in. This is a fantastic new service for our community!

February Lucky Squares winner is **Bill K.**
Congratulations We hope you enjoyed your meal.
Lucky squares only \$2 each to win a free lunch!
Please bring some change with you each month and see if you are a winner.

14	29	38	52	74
4	18	33	46	62
7	16	★	60	71
9	27	44	51	67
12	23	35	47	73

LIVING WELL WITH MND

An information day about living well with MND for people with MND.



Who should attend?

Living well with MND is a day seminar that extensively covers various topics important for people affected by MND. Various guest speakers will discuss topics that directly impact people with MND. This is an opportunity for all interested people to gain an in depth understanding of various topics as well as meeting others in the MND SA community.

WEDNESDAY 29TH MARCH 2017

City Mazda Stadium
57 Milner Road, Richmond SA 5033
10am – 4 pm

By the end of the day you will know more about:

- Motor Neurone Disease
- Living independently at home
- Eating well with MND
- Equipment that can assist
- Communication and MND
- Managing breathlessness and fatigue
- Finding services and support

Have your questions answered by a range of local health care professionals with expertise in MND. There is no charge for you to attend this program, but you will need to reserve your place.

RSVP to admin@mndsa.org.au or phone (08) 8234 8448 or freecall 1800 777 175.

Please note Living Well with MND will be offered on Wednesday 26th July & Wednesday 29th November 2017.

MAKE A DIFFERENCE TO THE LIVES OF PEOPLE WITH MND COMMUNITY VISITORS PROGRAM

Do you or someone you know want to contribute towards helping people with Motor Neurone Disease in SA? Have a little free time? Like to socialise? We might just have the thing for you!

Many of our clients feel isolated, because travelling from their home can get increasingly difficult. MNDSA is devoted to improve quality of life by promoting social interaction. We are commencing a new volunteer program titled the 'Community Visitor Program', where trained volunteers travel to client's homes for social interaction and support. This is not a personal carer role, but a socialisation and psychological support role. Want to meet up with likeminded people in similar situations and have a coffee and a yarn, then this might be just for you.

Please call MNDSA on (08) 8234 8448 if you are interested. We have an information meeting on Tuesday the 7th of March between 10.30am and 12pm for anyone wanting to know more about the program. We would love to see you there!

The legends at Stratco are supporting MND SA again in 2017...

We need teams of volunteers for Saturday **1st and Sunday 2nd April** at St Marys. Wanna help & have some fun? Call Carol on (08) 8234 8448.



HOW FUNDRAISING MAKES A PROFOUND DIFFERENCE AT MND SA...



\$250

A CLIENT SUPPORT SESSION WITH A KEY NOTE SPEAKER FOR ATTENDEES TO LEARN ABOUT DIFFERENT SERVICES AVAILABLE IN SA FOR PEOPLE WITH MND.



\$500

TWO HOME VISITS AND A CLIENT SUPPORT PACK.



\$1000

COMMUNICATIONS EQUIPMENT (LIKE AN IPAD)

Email Bianca today about how you can host an event to raise funds for South Australian client services.

CAN YOU HELP?



D O N A T E

All funds donated remain in South Australia. We need prize items, services or experiences for MND SA to use in raffles or auctions.

S P O N S O R

Can we partner with your business?

V O L U N T E E R

We need volunteers for events, fundraising, office support and community visits.

C O N N E C T

Can you connect us to a person or business who you think can help MND SA?

SUPPORT SOUTH AUSTRALIANS WITH MOTOR NEURONE DISEASE



EARLY BIRD TICKETS ARE AVAILABLE! WALK TO D-FEET MND SUNDAY 7 MAY 2017

This year, we are launching our exciting Walk to D-Feet beanie that is included as part of standard ticket along with refreshments and entertainment. So many of our community already have their walk t-shirts from last year – which you are welcome to wear again this year.

Don't worry if you don't have a t-shirt yet and would like one – another option we are offering is a ticket including beanie and t-shirt.

Although tickets can still be purchased on the day, we encourage you to take advantage of early bird tickets to secure your beanies. (Please note tickets purchased on the day will incur a higher price.)

You will also need to order ahead if you wish to secure a t-shirt as these will be made to order.

Purchase your tickets online: mndsawalk-2017.eventbrite.com.au

Email us if you have any questions and we look forward to sharing the day with you.

Know your MND health Professional Series – Jerry Packer

Jerry is a Registered Nurse and has over 16 years of nursing experience, working in a variety of fields. In his youth, he had a keen interest in emergency care and volunteered with St John Ambulance Australia and subsequently worked as an Emergency Nurse at the Queen Elizabeth Hospital. He has always had an interest in helping others and has worked in multiple nursing type roles, including surgical nursing and community based nursing, including Rehab Consultancy work contracted to Workcover. Also prior to his Nursing qualifications he worked as a Personal Care Assistant in multiple nursing homes.



Jerry is also a Remedial Massage Therapist, running his own business for 10 years, prior to commencing a full-time position at MNDSA. After hours, he is a lecturer at a Massage College in Adelaide, teaching Remedial Therapies to massage students.

Jerry is an avid supporter of community, regularly volunteering for Surf Life Saving SA. He commenced working as a Motor Neurone Disease (MND) Advisor in 2014, providing support to people with MND and their families, also providing education about MND to Aged Care Facilities and interested groups. He has enjoyed broadening his knowledge in the areas of Disability, Palliative Care and Aged Care. Jerry feels that the work done at MND is extremely important and something that needs to constantly grow and improve, hence the new development of the Community Support Program at MNDSA.

Jerry promotes and encourages change and is driven towards enhancing support to all South Australians affected by MND!

A BIG THANK YOU TO THOSE WONDERFUL MND SUPPORTERS WHO HAVE OFFERED TO VOLUNTEER THEIR TIME TO SUPPORT US AT THE CROWS VS GEELONG GAME ON THE 5TH OF MARCH 2017 AT THE CITY MAZDA STADIUM.



**DON'T
WAIT!!
TICKETS
ARE
ALMOST
SOLD OUT!**

YOU could win 7 nights' accommodation on SA CARE's luxury house boat when you purchase a \$5 Walk to D-Feet raffle ticket.

\$5 for a holiday of a lifetime...Tickets are selling fast! Call 8234 8448 and find out how to get yours! The raffle will be drawn at the event, Sunday 7 May.

Other fantastic prizes include:

- 2 day getaway package at The McCracken Country Club valued at \$600 (Conditions Apply)
- A Motoring Package including a service at Blackwood Dyno Tune & Service
- Dinner for two at Ambrosini's up to the value of \$150
- Two Gold Class tickets at Event Cinemas.

Each prize for the Walk to D-Feet Raffle has been donated by the following generous supporters:



YOUR MND SA TEAM

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