

YOU, ME & MND - CLIENT NEWS

UNTIL THERE'S A CURE THERE'S CARE

FOR SOUTH AUSTRALIANS WITH MOTOR NEURONE DISEASE



MND & Research – Adelaide University

On Thursday 15th of December 2016 MND SA's You, Me and MND Session was held at the Adelaide Sailing Club.

We had an amazing turn out! The increasing group sizes have reinforced the importance of these sessions to our community. We still encourage anyone and everyone to attend these sessions - Our clients, their families, friends and community members. All are welcome to attend to learn more about MND, network, discuss and socialise.



The increasing group sizes have made MND SA reassess the future of these monthly support group meetings for 2017. We have decided that a change of location is needed, to ensure a more suitable room, capable of accommodating larger groups; with access to presentation equipment and coupled with a special menu. It has been decided that this will be at the West Adelaide Football Club – right around the corner from the MND SA office. The address is: 57 Milner Rd, Richmond SA 5033 (at the City Mazda Stadium).

At this month's session, we were grateful to have Viythia Katharesan, Dr Ian Johnson and Shane Deery who are highly skilled researchers and lecturers at the University of Adelaide come and present at our meeting. They are a part of team that work at The Motor Neurone Research Group at the University of Adelaide. They have been looking for a cure for Motor Neurone Disease for many years.



Together they explained that they are working on finding a cure for Motor Neurone Disease and to this end they are looking at a number of factors including Neurotrophic factors, Gene Transfer and "Inflamm-aging".

They explained that researchers internationally still do not know what causes MND and that the only treatment currently available extends life for 3 months. Dr Ian Johnson explained that 90% of MND affects the aging population and that treatments and research in the past, have been developed and trialled on Young Motor Neurones. They have learnt that younger

Motor Neurones do not respond the same as older ones. They have discovered that older Motor Neurones can withstand much more injury and damage before cellular death than those of young Neurones. They are currently working on discovering what is 'so special' or different about older Motor Neurones and why.

The two key questions they are currently trying to answer are:

1. How do different ages of Motor Neurone's respond to injury?
2. What do they need to survive?

'Young motor neurones when faced with injury degenerate in large numbers and very quickly, compared to older motor neurones that appear to degenerate more slowly and in smaller numbers when faced with the same injury.'

It was also found that when Motor Neurones become injured Glial Cells come in to support the Motor Neurones. Research is being done to work out if they are a good thing or a bad thing.

They looked at a process of human aging which is characterised by a chronic, low-grade inflammation, and this phenomenon has been termed as "Inflamm-aging". Is the inflammatory environment around the old Motor Neurones different to Younger Motor Neurones? Therefore, helping them to survive? In the research, it was noted that there is a difference between Male and Female Motor Neurones responding differently, but thoughts are that there may be a 40% increase in survival in male adults in regards to the "inflamm-aging" process.

Some of the research also shows that some inflammatory proteins are lower in Motor Neurone Disease patients brains than people without MND of the same age, therefore this may also be useful for further research into the future.

Main points to date:

- Old Motor Neurones have a different response to injury compared to younger ones
- Chemicals that work to rescue young Motor Neurones DO NOT work as well with the older Motor Neurones
- The sources of these chemicals are different in the old & young Motor Neurones
 - a) Source 1: Muscle
 - b) Source 2: "Supporting Cells" = Glial Cells
- Older Motor Neurones are sitting in a highly inflammatory environment vs. younger ones that are not
- When trialled Younger Motor Neurones with a similar level of inflammation to older ones:
 - c) No change for females
 - d) Appear to have an improved survival rate in males
- MIP-1b and IP-10 are enzymes used in the immune and inflammatory response in the body. They have been found to be potentially Neuro-protective and are high in normal ageing but found to be lower in MND patients.



Happy Holidays

MND SA will close at 4:30pm on Thursday 22nd December and reopen 9am, Monday 9th January 2017. If you have an MND related enquiry during this time, please refer to our website mndsa.org.au or give us a call on our return.

If you have a medical issue, please call your GP. Alternatively, between 3rd January and 6th January 2017 you can call MND Victoria helpline on 03 9830 2122 who will be able to deal with any general MND related enquiries.

NEW LOCATION & NEXT SESSION!

Our next meeting will be held on Thursday 19th of January 2017 at our new location at the City Mazda Stadium, 57 Milner Rd, Richmond SA 5033.

Marianna Bernal, who is a Physiotherapist working with Spinal Cord Injuries Australia (SCIA) will be our guest speaker. SCIA have opened a new rehabilitation gym called Neruo Moves based at the Parks Recreational Centre. They offer exercise therapies to people with a neurological condition and can tailor a program to suit individuals and small groups of people with MND. Their aim is to decrease the barriers that arise for people with a disability to access exercise services. A large percentage of their services can also be included in community care packages.

RSVP IS ESSENTIAL AS SPACES ARE LIMITED! PLEASE CALL 8234 8448.

The meetings 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.

Coming soon in 2017 – MND SA will run a ‘know your MND health professional’ series, which will include the personal bio’s of various MND health professionals and service providers statewide and what drives them to do the amazing work they do.

Thursday the 16th of March is a client led discussion group – we are still looking for more people willing to present or discuss topics close to their heart. Please contact us to discuss. No topics are off the table and everyone is invited to get involved.

UPCOMING INFORMATION SESSIONS:

If you would like to volunteer at a You, Me & MND session please let give us a call! You would assist with the set-up of the event and make coffee/tea for guests.

WHAT WOULD YOU LIKE TO TALK ABOUT?

We welcome your feedback, so let us know what topics you are interested in and we will plan 2017 with your ideas in mind!

Our community is growing...ask us how YOU can get involved.

admin@mndsa.org.au



UPCOMING YOU, ME & MND SESSIONS

Thursday 19th January 11am

Marianna Bernal, Physiotherapist working with Spinal Cord Injuries Australia (SCIA)

Thursday 16th February 11am

Mary-Louise Rogers from Flinders University – local SA based research update

Thursday 16th March 11am

Client Led Discussions

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 20th April 11am

Public Trustee – Wills, Power of Attorney and Advance Care Directives

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.

Registration

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.

MND SA FAMILY INFORMATION EVENING

MND SA warmly invites you, your family and friends to an information evening specifically designed to educate and support those affected by a loved one's diagnosis of MND.

Who should attend?

MND SA's Family Session is an opportunity for people to learn about MND and the sources of help available when you are a member of the MND SA community. Information will assist friends and family of a person who is diagnosed with MND to have a greater understanding of the disease, and how they can assist.

The session will include:

- An overview of MND
- Living well with MND
- How MND SA supports its members and families
- How to access support services
- Opportunities for people to discuss individual needs and concerns with MND Advisors.

WEDNESDAY 22ND FEBRUARY 2017

City Mazda Stadium, 57 Milner Road, Richmond, SA 5033

Parking is available at the rear of the club.

6:30pm-8:30pm (please arrive 10 minutes early)

Tea and coffee supplied. A set menu at a discounted rate will be available for evening meal. More details to come.

Registration

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

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



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

CAN YOU HELP?



DONATE

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

SPONSOR

Can we partner with your business?

VOLUNTEER

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

CONNECT

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

SUPPORT SOUTH AUSTRALIANS WITH MOTOR NEURONE DISEASE



SAVE THE DATE WALK TO D-FEET MND SUNDAY 7 MAY 2017

Walk to D-Feet MND symbolises the hope that Motor Neurone Disease will one day be eliminated whilst also serving as a memorial for those that have been lost to the disease. Participants organise teams made up of family, friends and colleagues, regardless of age or fitness levels, to raise funds for MND SA services.

Walk to D-Feet MND 2016 saw record numbers in attendance with over 800 participants. The event is a 4km walk followed by family fun day held at the Adelaide Sailing Club, West Beach.

2017 Raffle books are now available and the prizes are fantastic!! \$5 per ticket for a chance to win:

1st prize: 7 nights' accommodation on **SACARE's** Imagination Houseboat valued at \$3,500
(Conditions Apply)

Imagination is a fully equipped wheelchair friendly houseboat on the River Murray with 5 large ensuite cabins as well as a heated spa and sun deck. A luxury break for up to 10 people.

2nd prize: 2 day getaway package at **The McCracken Country Club** valued at \$600
(Conditions Apply)

3rd prize: Motoring Package including a service at **Blackwood Dyno Tune & Service** with a car wash kit

4th Prize: Dinner for two at **Ambrosini's** up to the value of \$150

5th Prize: Two tickets to Gold Class at **Event Cinemas**

Call us on 8234 8448 to organise some raffle books to sell!



Save the date...

Xmas in July Gala Dinner



Saturday July 22nd 2017

YOUR MND SA TEAM

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