



The magazine of the Southampton & Winchester
Motor Neurone Disease Association Group

Southampton & Winchester Group

June 2019



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MNDa news from
the local area...

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If you have any comments or feedback about the magazine and its content, please do not hesitate to get in touch

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GLOBAL AWARENESS DAY

With Global Awareness Day on the 21st June, the month is always an important date in the calendar and now MNDa celebrates their 40th anniversary it makes this year even more significant.

SCRAP 6 MONTHS



Scrap the 6 months restriction for Special Rules



As part of our campaign we urge people to sign our petition calling for a speedier and less difficult process for people with a terminal illness to claim welfare benefits.

The Association hopes that so many people get on board that by the time the petition is handed into 10 Downing Street in early August there will be at least 17,070 signatories which will match the number of people who have died while waiting for a decision on their Personal Independent Payment in the last six years.

This is an awful statistic so we ask you to sign the petition yourself and share/pass on the link to others so they too can help us make a real difference.

To sign the petition follow the link below or scan the QR code with your tablet or smartphone
<https://e-activist.com/page/33936/petition/1>



MONTHLY MEETINGS

The Southampton & Winchester Group have been treated to some fantastic and insightful Speakers at our last few Monthly Meetings and we must thank all those that arranged and organised their visit and those in attendance for supporting our branch of the charity too.

From Professor Karen Morrison who visited us in May and revealed promising research developments in trial research with SOD1

to our informative talk on 'Power of Attorney' and the importance of making a living will - we have all enjoyed learning and hearing from our visiting guests and passing the knowledge onto our loved ones and colleagues.

July's visiting speaker will be enlightening us on the impact of Music Therapy so if you would like to join us for another illuminating evening of discussion please

COFFEE MORNINGS

Did you know that we also hold Coffee Mornings as well?

Ideal for anyone not able to make the Monthly Meetings or for those that would like to meet more people, our Coffee Support Meetings are held on the third Monday of every month at the Hazel Centre in the Countess Mountbatten Hospice, from **11:00am-12:30pm**.

We invite people living with MND, their families and carers to pop along for a chat once a month with our next events being held on **Monday 15th July** and **Monday 19th August**.

See the back page for all the details!



MOTTISFONT MUNCH



It was wonderful to see so many supporters of MNDA enjoying our annual trip to Mottisfont Rose Gardens on the 6th June.

The Afternoon Tea is a lovely opportunity to get together with like-minded people in a beautiful setting and we hope the tradition continues for many years to come.

Thank you to everyone who attended, volunteered and supported the Motor Neurone Disease Association that day

We had a ball!



come along to our next Monthly Meeting on Tuesday 9th July at Oasis Academy, Lordshill, Southampton from 7:00pm onwards.

Whether it is your first or fiftieth time joining us everyone is welcome with open arms and refreshments.

Please also note our location is fully accessible for all types of wheelchairs and disabilities with modern toilet facilities to suit all needs.

July's Monthly Group Meeting;
Tuesday 9th July 2019 - 7:00pm-9:00pm
Oasis Academy Lordshill, Redbridge Lane,
(off Romsey Road), Southampton, SO16 8FA



Please send your stories and photos to sara.alrashed12@gmail.com or pass them on to your AV.



ALISON MCGREGOR ADVENTURES

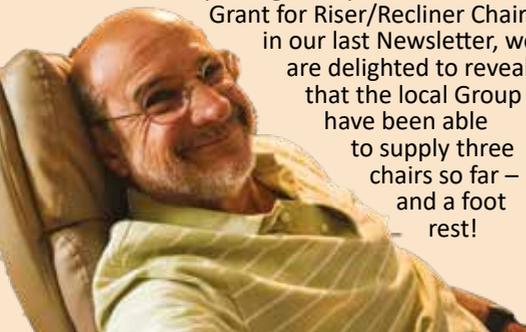
Speaking of annual traditions, we couldn't forget our dreamy excursions on the 'Alison McGregor'. A fully decked out disability friendly boat, the Alison McGregor has sailed along the Solent with MNDA supporters for many years now.

Welcoming those living with MND, their carers and families – the six wheelchair spaces fill up fast so if you would like to join us on one of these free voyages please reserve your space with Rosemary Rockett at 023 8089 1842.

The Alison McGregor always sets sail from Hythe Marina with two dates booked for MNDA this year - reserve either Sunday 7th July from 10:30am-12:30pm or Sunday 22nd September from 2:00pm-4:00pm. Route determined on the day.

ESSENTIAL EQUIPMENT

Since our reporting of a specialised MNDA Grant for Riser/Recliner Chairs in our last Newsletter, we are delighted to reveal that the local Group have been able to supply three chairs so far – and a foot rest!



We know that these chairs are invaluable pieces of equipment to anyone living with MND and help with everything from dressing to eating so its wonderful to see those that need these items benefiting from the grant.

The Association is still able to provide the £750 needed to anyone else looking to improve their quality of life in this way, so for more information please speak to your OT/AV who will be able to put you forward for the grant.

JERSEY JOLLIES!

With grants in mind.. did you know that there are also holiday bursaries that people living with MND and their families, can apply for?

Specifically for stays on the island of Jersey, full or part funded financial assistance may be offered towards travel and accommodation. For more information contact your AV for more information.





ROB'S RUN

You may remember in our last Newsletter we told you about Rosie Perrett's son Rob running in the Brighton Marathon for the first time, in memory of his Dad.

Completing the coastal event Rob Perrett pulled on the MNDa vest and managed to cross the finish line raising over £1400 in the process!

Thank you so much to everyone who donated and a massive thank you and well done to Rob!

What an achievement!

JUST GIVING

JustGiving™



When talking about raising money and gift aid it can sometimes become a bit confusing – especially when so much happens online and you're not sure who and where your hard earned fundraising will go.

That is why we are now thrilled to inform you that the popular fundraising

website 'JustGiving' will now no longer charge charities 5% on each donation - making every penny raised through their website 100% certain to reach the charity you want it to go to.

This means Just Giving will become a 'fee free platform' and charities will now always receive full donations raised in their name.

Please also remember that when setting up or donating to an event or account online you must specify WHERE you want your donation to go as many people do not realise that

these donations will not be sent to local groups unless stated so in the initial set up.

If raising money specifically for the Southampton & Winchester Group online please always ensure you tick the box/state clearly the local Group, as money raised for 'MNDa' gets sent to National Office in one big batch making it difficult to separate and differentiate between accounts.

We have had a few people upset over these confusions so if you need any help please do not hesitate to contact us.



TARA'S WING WALK

With fundraising in mind, meet Tara Stannett who was introduced to the Southampton & Winchester Group in May after losing her mother to MND just 3 months after diagnosis in January.

Tara says her mother Jan Blake was unlike any other 83 year old.

Young at heart and always the first on the dance floor, Jan loved the outdoors, cycling and gardening and Tara promised her that they would raise money for the Association to help find a cure for the cruel disease. ➡

➤ TARA'S WING WALK

Tara says, "I did tell Mum that I was going to do a Wing Walk....by the look on her face I could see that she was not happy with that idea!

I wouldn't say that Wing Walking has been on my bucket list but I have always been interested in doing something scary like that.

I am not an adrenaline junky at all and I don't even like roller coasters so doing this will be a HUGE challenge for me and I will be completely out of my comfort zone."

Tara takes on her challenge on the 6th September at 10.30am at RFC Rencomb Airfield in Cirencester and is hoping to get as much support as possible.

Please visit <https://www.justgiving.com/fundraising/tarastannett> for Tara's story and to donate if you can.

THANK YOU'S

We are always so grateful for your generosity. Without your donations, legacies and gift aids we would not be able to support everyone living with MND in our area as quickly as we currently do.

It is thanks to you that we are able to help those in the worst times. Since the last Newsletter we have received more kindness and wish to especially thank everyone who donated to the charity in memory of Roger John Perry and the Royal Hampshire County Hospital Nurses League who donated in memory of Elizabeth Brock.

We would also like to thank Jane Anderson for collecting on behalf of MNDA at Winchester Cathedral's Gift Shop (and all those who gave their loose change for the box) as well as everyone who donated to the collection box at 'The March Hare' in Winchester.

Thank you also to everyone who has bought some form of MNDA merchandise in the last few months. Every penny will go towards helping those living with MND in Southampton and Winchester.



MEDSOC

A great big shout out must go to the Southampton & Winchester Group's Social Media Officer Adama, for campaigning for a MNDA section within the Medical Societies at Southampton University while training to become a doctor.

Her hard work finally paid off and an inaugural meeting was set up to plan and lay the foundations for a MedSoc branch with great success.

Our Group also had the pleasure to meet several members of the new Society and we're overjoyed that so many future medics will understand and be able to identify the symptoms of the disease.

We have also just heard that the Society has been chosen as one of main charities of the year within the university so we hope to receive a few donations over the next few months too!

Adama says, "What we are bringing is the much-needed awareness about this debilitating disease to medical students in Southampton....watch this space!" Wow!

We can't wait to see the Society grow – well done Adama and thank you for championing MNDA!





LYNDSY LEAVING...

Sadly, this month we say farewell to our Group fundraiser Lyndsy Ambler.

Joining us as a student, Lyndsy graduated University and now spreads her wings further afield to start a new job and new adventure.

Thank you Lyndsy for all your support at the Southampton & Winchester Group during your time with us – good luck, don't be a stranger and hopefully see you again soon!

NOTICE BOARD

Group/ Open Meetings

(Second Tuesday of each month)
Oasis Academy, Lordshill, Redbridge Lane
(off Romsey Road), Southampton SO16 8FA
7:00pm – 9:00pm

Next Meetings

9th July & 13th August

Coffee Mornings

15th July & 19th August

Other Events

Alison McGregor Trips
7th July & 22nd September

Volunteering Roles

Group Leader
Group Fundraiser
Coffee Morning Volunteers

YOUR CONTACTS

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Facebook: facebook.com/mndsouthampton
Twitter: @MNDASoton

MND Connect **T:** 0808 802 6262
Registered Charity No. 294354

**MOTOR NEURONE DISEASE ASSOCIATION
SOUTHAMPTON/WINCHESTER GROUP**

COFFEE MORNING

**EVERY 3RD MONDAY
OF THE MONTH -
11.30AM**

**LOCATION:
HAZEL CENTRE
COUNTESS MOUNTBATTEN HOSPICE,
WEST END, SOUTHAMPTON SO30 3JB**

To RSVP and to ask about
transport/accessibility: contact Rosemary
Rockett on 02380891842 or
mrs_rockett@hotmail.com

