

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

Southampton & Winchester Group

August 2023



All the latest MNDA news from the local area MNDA Scissors Dancing by Martin Farrow

# motor neurone disease

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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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## GRATEFUL ON GLOBAL AWARENESS DAY

Thank you to everyone who attended or organised a fundraising event, helped create awareness of MND and dedicated their time or expertise to the Association for Global Awareness Month last June.

We are so grateful for the profile MND is now getting in the media and as a result in our own local communities too.

The whole month was geared towards the 21st June when Motor Neurone Disease was truly put in the spotlight with people up and down the country spreading the word either in person or online.

In our own corner of the world we had the Southampton Guildhall lit up in the Association's orange and blue once again to create a talking point with local councillor's and the general public.

Local members Dawn and Sara managed to grab a few shots of the building as the sun set but please let us know if you saw any other buildings lit up too.



We also had Graeme and Jackie's Open House Day that was a wonderful fundraiser that managed to raise a staggering £1023.37! N

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Guests were invited to visit the couple and share in refreshments, stalls and a raffle. Jackie says,

"It was a lovely sunny day and everyone enjoyed coffee/tea and as much cake as they could eat!!

We estimate over 60 people attended the event and we also received generous donations from those who were unable to attend on the day."

A big thank you to everyone who donated so generously and a massive well done to Graeme and Jackie who have also been planning another fundraising event for MNDA!



## ON YOUR FEET FOR NANNY REET

Extending her fundraising through Global Awareness Day and beyond is our very own Rita Elsey who has a brilliant JustGiving campaign called 'On Your Feet For Nanny Reet'. With a host of events and activities being organised, Rita's friends and family have come together to show their love for her by supporting a worthy cause. From taking oars for sponsored rows to a royally raucous 'Race Night', Rita and her beloved crew have raised over £3,000! Thank you to everyone who has helped to contribute to such a fantastic amount – the money you raised will continue to support local people living with MND and ensure that everyone gets the help they need.



## CASH FOR COPPER WIRE

Did you know that you can fundraise for the Motor Neurone Disease Association in many different ways?

One way Margaret Weaver is adding to our pot is by striping copper wire. Using left overs, off cuts and used or unwanted cord, Margaret takes the copper and makes money to donate back to MNDA.

If you have any you would like to donate, please bring the items with you to the next Monthly Meeting where Margaret will be happy to take it off your hands and turn it into something for a good cause.

Please note – All money raised for MND goes to the Association but only funds specified for the Southampton & Winchester Group will directly support local people in our region.

We are so appreciative of any contributions but if you would like to direct your fundraising locally please stipulate the Southampton & Winchester Group on all cheques and JustGiving donations.





## A MESSAGE ON VOLUNTEERS & CARERS WEEK

With so many fantastic people volunteering for MNDA during June it was fitting that the month should also hold Volunteers & Carers Week.

Running consecutively from the start of June, each week celebrates and recognises the people and hard work that goes into each role and how we as a local Group and as a National Association, would not be able to operate without them.

The contribution of volunteers and carers change lives, and we are forever grateful for your firm commitment to us all.

Thank you to everyone who fulfils one of these roles in our region all year round.

You are so valued and we want to say a huge thank you to you all!

# **COASTING ABOARD** THE ALISON MCGREGOR

We've been lucky that the summer weather has held for our last two cruises along the Solent on board the Alison McGregor boat.

Specially equipped to hold six wheelchair users and their guest, the boat sails from Hythe Marina each time and takes a different route according to the tide. Trips are free for people living with MND and we still have one more journey booked for this year!

If you would like to join us on Tuesday 5th September from 2:00pm-4:00pm, please contact dawn.pond@mndassociation.org to book your place.



### MND-SMART Clinical trials for MND

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Thank you to everyone who has been attending our Coffee Morning and Monthly Group Meetings! July's Monthly Group Meeting was our busiest yet and it was great to see so many faces chatting, sharing ideas and discussing the points raised by our guest speaker.

Last month we were kindly joined by Clare Erridge from the Southampton MND Care Centre who many people knew as one of the first contacts made after being diagnosed with the disease.

Clare shared the current objectives of the work they do at the MND Centre - as well as asking for input in the improvements they would like to make in helping to support local people living with the illness, too.

From supporting people on the CALM and DIAMOND studies, to explaining the positives of registering early on the MND-SMART study, Clare was able to inform our members on each and hear feedback from us to gain another perspective.

If you would like information on any of the studies mentioned please contact Clare Erridge at uhs.southamptonmndcarecentre@ nhs.net

Earlier in June, Sue Bell from the Mountbatten Hospice visited us at our Monthly Group Meeting to talk all about what the Hazel Centre has to offer people living with MND.



## MONTHLY MEETINGS

From gardening activities hosted by the 'Down to Earth' Farm to music and art classes - Sue wants to break the stigma around hospices and how they are only generally considered for end of life care.

Sue demonstrated to us how much they have to offer and the support they can give at any time.

With a few of our members all ready attending the Hazel Centre for activities and respite, they were able to share their experiences and give an insight into the classes or support they received too - and we all agreed what a jam-packed timetable the Hazel Centre has!

For more information on activities you can take part in, please contact the Hazel Centre at https://www. mountbatten-hampshire.org.uk

This month we are excited to announce we will be holding a Tai Chi workshop during our Monthly Group Meeting!

Taking place on Tuesday 8th August from 7:00pm-9:00pm, the session is suitable for all abilities and is a great way to relax, unwind and learn a few techniques to take home and practice yourself!

Our previous workshops have been tremendous fun so please join us for free on the 8th August at Oasis Academy Lordshill!

# MND IN THE COMMUNITY

On Sunday 16th July, Oasis Academy Lordshill invited the Southampton & Winchester MNDA Group to set up a table and create awareness of the disease as well as the regional Group at their first 'Community Open Day'.

Established to encourage the local community to get involved in organisations and activities that are happening around them – three volunteers from the group (along with a few cheerleaders) popped along and decked out a stall with MNDA colours and balloons.

Displaying lots of infographics and leaflets, the stall had lots of traffic on the day and was even lucky enough to gain a few donations in a collection tin too!

Thank you to everyone who helped put the day together, manned a shift on the table and spoke to eager visitors who wanted to know more about MND.

Although not a fundraising event, the Group collected just under £10 as a little bonus too!



# ARE YOU A VETERAN WITH MND?

Have you been in the Military and are now living with MND?

A new online Group with other people who have a similar

background is looking for you!

Please join us next month via Zoom to chat or listen in as we all come together.

Contact Dawn.pond@mndassociation.org for the link and we'll put you in touch!





# Please join us on the third Friday of each month 3 - 4 pm

We would like to welcome all veterans to join us for a different type of support. Not just about MND but about you and your background and some common interests. A safe place to talk with like-minded people.

Please let me know if you would like to join us and I will send you a Zoom link to join.

### Please contact: Dawn.pond@mndassociation.org

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### www.mndassociation.org

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## HOME AND WELL SCHEME

Citizens Advice now offers a Home and Well scheme that works together with specialist organisations to ensure anyone in the Hampshire and Isle of Wight area is able to return home quickly and safely after a hospital stay.

To enable the best recovery possible, the scheme also ensures patients return to a comfortable home so will assist with;

- Energy/water tariff advice
- Priority Service Registration (PSR) – a service that will ensure the patients will receive additional support should they receive a power cut or water shortage
- Income maximisation
- A complete wrap-around/ signposting service – referring to community and other organisations for a range of social issues

Patients must be referred by a professional but once accepted the project also offers guidance for any other issues that may arise from housing, employment and relationships.

### Please visit

https://citahants.org/home-and-well/ for more information.



## **NOTICE BOARD**

NoticeBoard – Monthly Meetings - Second Tuesday of every month - 7:00pm-9:00pm In Person - Oasis Academy Lordshill Redbridge Lane (off Romsey Road) Southampton SO16 8FA

Online – Please get in touch for the link.

**Coffee Mornings – Third Monday of every month** Hillier Garden Centre, Botley, SO30 2EZ

Volunteering Roles – Please contact Dawn Pond - dawn.pond@mndassociation.org

Southampton Care Centre - uhs.southamptonmndcarecentre@nhs.net

Wheelchair Queries - Ann Buchanan – 01604 611694 wheelchair queries@mndassociation.org

### YOUR CONTACTS Banker of Donations and Main Contact Mrs D Pond 64 Salisbury Poad, Totton

64 Salisbury Road, Totton, Southampton, So40 3JB Magazine Editor Sara Al-Rashed E: sara.alrashed12@gmail.com

### **Fundraising:**

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### **Group Websites:**

W: mndsoton-winch.org.uk W: justgiving.com/mndasouthampton Facebook: facebook.com/mndsouthampton Twitter: @MNDASoton MND Connect T: 0808 802 6262 Registered Charity No. 294354



## **MND** Association care information

We produce a wide range of care information to help people with motor neurone disease (MND), their carers and families, including children and young people. Our aim is to help everyone involved achieve the best possible quality of life while meeting the daily challenges of the disease.

### Our range includes:

- guides
   larger publications, offering comprehensive overviews to help throughout the course of the disease
- information sheets shorter publications, which focus on specific symptoms or subjects such as welfare benefits
- leaflets and cards to help with specific needs, including a card to make people aware that a person has MND.



Find our publications online at: www.mndassociation.org/publications or contact our MND Connect helpline to order printed copies.



For support and further information: MND Connect 0808 802 6262

www.mndassociation.org