# motor neurone disease association

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

## Southampton & Winchester Group

April 2024



All the latest MNDA news from the local area Crafting Fundraising for MNDA see page 7



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#### **Magazine Editor:**

Sara Al-Rashed sara.alrashed12@gmail.com

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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## **COFFEE MORNING** CHANGES LOCATION

Our 2024 MNDA Support Coffee Mornings have started with a bang!

With over 24 people joining our last event, the time has now come to up sticks and move the gathering to a larger venue that can further accommodate our growing group.

From Monday 15th April, every Southampton & Winchester MNDA Support Coffee Morning will now be held at The Bell Inn at Brook, SO43 7HE.

With the same cosy chit-chat at the usual regular time slot of 11:00am-1:00pm, the third Monday of every month promises everything you know and love - plus a few new faces too!

We look forward to our first visit to the Bell Inn this month and can't wait to see all your photos of the day and hear your feedback about the new venue tool





#### New Coffee Morning Location - The Third Monday of each month 11:00 - 13:00

# Please join us at the Bell Inn, Brook, SO43 7HE for our informal support group for people affected by MND

It's a lovely large room with a cosy and comfortable feel to it in the heart of the New Forest. This is an opportunity to meet others on a similar journey in a safe and comfortable environment. We have our lovely trained Volunteers on hand to ensure you are looked after and they can support you with any questions you may have. See you there

## Please contact Dawn Area Support Co-ordinator for more information Dawn.pond@mndassociation.org







www.mndassociation.org Francis Crick House, 6 Summerhouse Road, Northampton, NN3 6BJ Registered charity no. 294354 | Created in RightMarket - 11/3/2024 - 15:22:49



#### **FUNDRAISING AT THE FOOTBALL**

AFC Totton Football Club are continuing their support of the local MNDA Group by allowing us to hold another Bucket Collection Day at their ground in Testwood on Saturday 6th April.

If you, your family members or friends are able to help us by collecting loose change on this date please contact Dawn Pond who will be able to set you up and provide all the details of the day.

'Shifts' range from 2:00pm-5:00pm with all expenses and refreshments paid for and provided.



We're looking for as many people to pitch in and help create awareness as possible so please get in touch with Dawn at dawn.pond@mndassociation.org to find out more!

## ALL ABOARD ALISON MCGREGOR

Local AV Jean Block has very kindly booked several day trips out on board the very special 'Alison McGregor' boat this year. The vessel is equipped to comfortably hold six wheelchair users and guests along the Solent, on specified days for people living with MND.

Trips are free to all who book but unfortunately spaces are limited – and popular – so we advise you to get your space quickly!

Choose between either Spring/Summer dates; Sunday 26th May – 2:00pm to 4:00pm or Saturday 22nd June - 2:00pm to 4:00pm



by contacting Jean on 02380 845116 and leaving a message. Both dates leave from Hythe Marina and will take a course depending on the tide and conditions of the day.

If you miss out this time we hope to have another date for early Autumn so please keep checking out the latest issue for more information.

## MND CAN GET IN THE SEA

#### Have you heard about David and Alice Baker's blog?

Following David's diagnosis of MND in July 2023, he and wife Alice decided to document their journey living and caring for someone with the illness.

In an excerpt taken from the latest post David writes, "I've always loved writing, whether it be my thoughts, stories, lists, poems, song lyrics, or taking on the role of historian for the football clubs, musical groups, companies, or establishments that I have been involved in. This has continued into the digital age, recounting timelines and adventures on social media formats.

I'm joint or sole administrator on six Facebook pages, and take great care and pride in the content that is published, which is then rewarded by the satisfaction reflected back onto me by the comments, and conversations that my words engender."



To follow David and Alice's adventures check out their blog at https://tinyurl.com/utnp5es7 that also features all their recent fundraising and details about up-and-coming events including a Quiz at the Island Sailing Club at Cowes on the Isle of Wight on Wednesday 24th April. For more information on the quiz or to donate to the Baker's Just Giving page please take a look at the following links;





Quiz - https://tinyurl.com/rue248ck





Just Giving page https://tinyurl.com/2c26ps32





A massive thank you, as always, to everyone who continues to support and think of the Southampton & Winchester MNDA Group in their donations and fundraising events. This month we would like to send a special shout out to Patrick McGonigle who raised over £1,800 by having a Tom Jones tribute and presented a wonderful cheque at a recent Coffee Morning - and to all who contributed to our collection tin at the Oasis Open Day last year.



Through donations like yours we were able to provide almost fourteen thousand pounds in grants to local people in 2023 – including providing eleven special chairs to those who need it the most.

We never take your generosity for granted and want to thank everyone for all the help they give us so that we can continue to help people living with MND.

Thank you everyone!

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.

### COST OF LIVING SUPPORT FUND

Don't forget that you can still apply for a 'Cost of Living Support' Fund.

The grant does not affect any other applications or contribute to your yearly £3,000 allowance.

The Cost of Living Support Fund is there to help you and your family during this financially challenging time and can be used towards household bills and your regular food shop. The grant is capped at £350 but can still be a valuable addition in your bank account so please consider applying if you would benefit from a little top up.

Apply here:https://tinyurl.com/mwsryc9d





## **GETTING CRAFTY IN MARCH**

Last month the Association challenged members to 'Craft It' and collect sponsorship for their efforts. Volunteers and supporters could choose to knit, paint, draw, crochet or do something completely different in an attempt to raise extra funds for local groups.

Our own AV Margaret Weaver took up the challenge with her daughter, crafted everyday and made cute Easter chicks to give as gifts over the bank holiday.

The skill and patience needed to create such a lovely token is not lost on us and we thank you both for contributing to our great cause.

Thank you also to everyone who donated and purchased their crafts. You are all fantastic!

Did you take part in a MNDA Campaign or Challenge? Let us know and get it featured in our next issue!

## VINTAGE MNDA

We are very fortunate to have volunteers who have supported the local MNDA Group for many years.

Over that time our volunteers have organised, run or attended many events and activities and collected many photographs and friends along the way.

During a recent clear out a few of these photos were found and we thought it would be fun to share them with you and recall old memories.

Do you have any old photos of an MNDA event or party?

Please get in touch and we can share them too!





## **ALL ROADS LEAD TO ROME**

We are proud to share with you news of Rob Duffin's involvement in the 'My Name'5 Doddie' Foundation - 'All Roads Lead to Rome' Challenge.

Rob, who is local Voice Banker volunteer Nicky Duffin's son has been tirelessly supporting MND and even took part in a mammoth sponsored cycle last year. Not content with stopping there though, Rob joined 'Team Babble' in Edinburgh to deliver the Scottish Rugby ball to the national team before their match in Rome using only a push bike to travel the whole route.

Awed at Rob's achievement Nicky tells us, "Our boy Rob, teamed with Matt and James and their driver left London on 29/02/24 and arrived in Murrayfield at midnight to start the 'All Roads Lead to Rome' Doddie Ride 2024 as team Babble.

They cycled approximately 2527km from Scotland to Rome to deliver the rugby ball for the Scotland v Italy 6 nations rugby game leaving on Friday 1/03/24 and arriving on the 8/03/24

ready for the game the next day. They battled strong southerly winds and freezing temperatures in UK as well as rain, snow and land slides across roads up in the hills past Lake Constance. They then cycled over the Alps and down to Lake Garda doing approx 500 km each day between them.

The ball was delivered onto the pitch and they all got to watch the match, even if it was from up in the gods!"

Nicky, the whole Duffin family and everyone at the Southampton & Winchester MNDA Group are all so proud of everyone involved in 'Team Babble' and feel so lucky to have you helping us in our fight against this terrible disease.

We know that the 'Babble Rabble' have many more events and fundraising activities planned for the year and we wish them lots of luck in their goal to raise £250,000 for the Foundation. We're behind you all the way!





# Please join us with your children or grandchildren for a lovely memory-making day

Your local group is happy to fund a family day out for anyone living with MND and up to 4 people. You will have free access to the park for the day and we will have a room if you need any personal space away from the crowds where our Volunteers will be on hand to support you with light refreshments. We will need numbers so please ensure you let us know who is coming with you and not just turn up on the day.

We look forward to seeing you there. Children under a Metre are free so they wont be included in your +4.

#### Please contact Dawn Pond Dawn.pond@mndassociation.org for more information and to book your places.





#### www.mndassociation.org

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#### MND care centres and networks

The MND Association provides funding towards MND care centres and networks across England, Wales and Northern Ireland. These are centres of excellence that bring together internationally recognised expertise in the diagnosis and symptom management of motor neurone disease (MND).

MND care centres and networks are committed to person-centred care. They coordinate the care of people with MND, involving a range of different professionals and community services. They also conduct research into MND and improving care.

Locate your nearest care centre or network at www.mndassociation.org/carecentres



Care centres and networks:

- develop expertise in the management and treatment of MND including, for example, nutritional and respiratory support
- conduct groundbreaking research into care management, and world-class clinical trials and biomedical research
- provide a resource for health and social care professionals through information, education and sharing good practice about MND.

For support and further information: MND Connect 0808 802 6262

www.mndassociation.org

#### **NOTICE BOARD**

NoticeBoard – Monthly Meetings - Second Tuesday of every month - 7:00pm-9:00pm – Now back to Face-2-Face!

**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 in our new location starting in April!

Volunteering Roles – Please contact Dawn Pond	dawn.pond@mndassociation.org
Southampton Care Centre	southamptonmndcarecentre@uhs.nhs.uk
Wheelchair Queries	Ann Buchanan – 01604 611694 wheelchairqueries@mndassociation.org

#### YOUR CONTACTS

Banker of Donations and Main Contact Mrs D Pond 64 Salisbury Road, Totton, Southampton, So40 3JB Magazine Editor Sara Al-Rashed E: sara.alrashed12@gmail.com

**Group Events Contact** 

#### Fundraising:

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.

#### **Group Websites:**

W: https://www.mndassociation.org/support-and-information/local-support/ branches/southampton-and-winchester-group W: justgiving.com/mndasouthampton Facebook: facebook.com/mndsouthampton Twitter: @MNDASoton MND Connect T: 0808 802 6262 Registered Charity No. 294354 Scan Me



#### **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