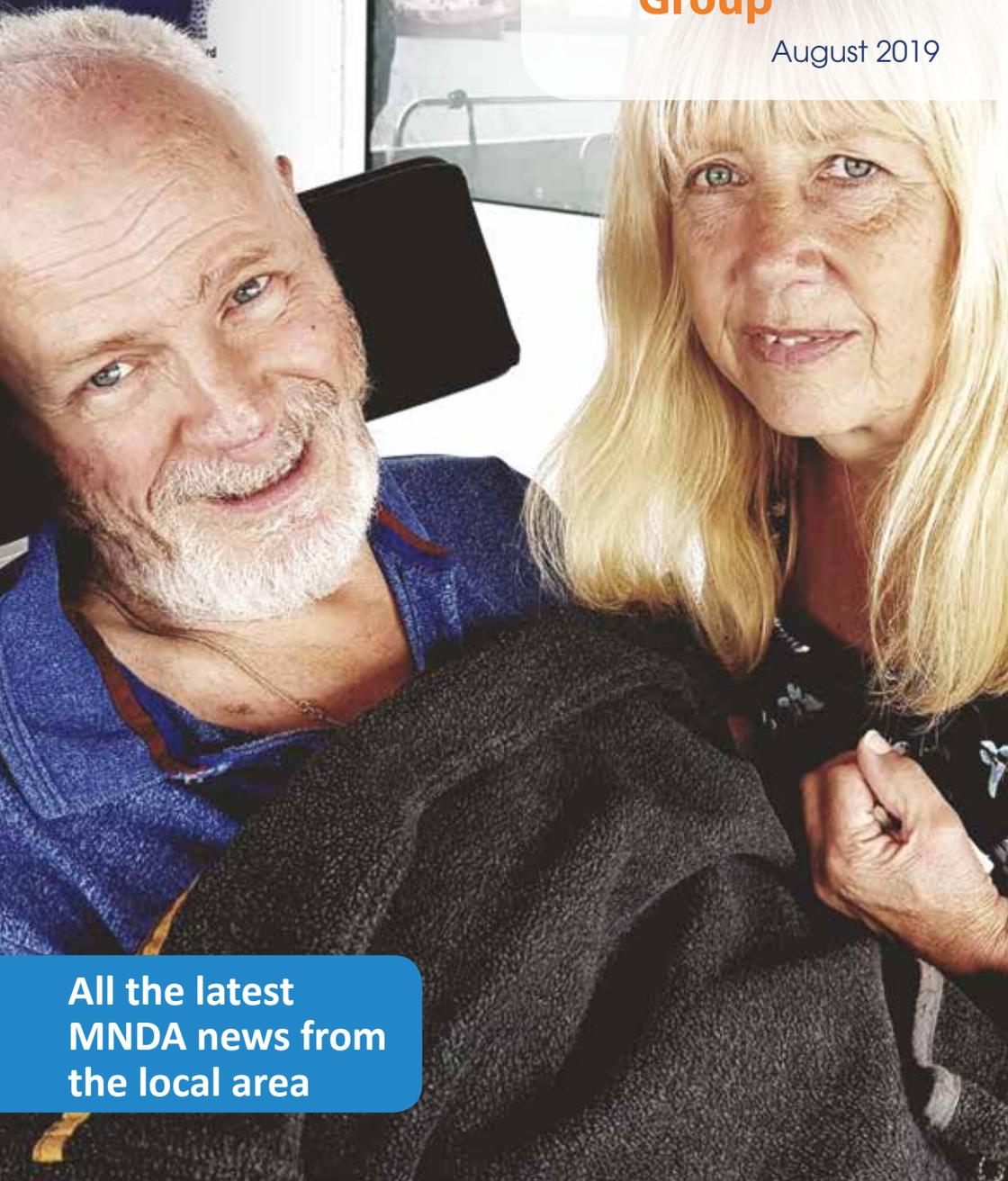




The magazine of the Southampton & Winchester  
Motor Neurone Disease Association Group

# Southampton & Winchester Group

August 2019



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# MONTHLY MEETINGS



A big welcome to everyone who has recently been joining us at our Monthly Meetings. It is always great to see new and returning faces and we'd love to see even more of you when we host MNDA researcher Rose Evill on Tuesday 13th August.

Rose, who was featured in our February magazine earlier this year asking for participants in her and Sally Wheelwright's 'DiaMoND Study', is aiming to develop a web-based patient aid to help those with MND decide on fitting gastrostomy feeding tubes - and when.

At August's Meeting, Rose will be explaining the 'DiaMoND Study', her progress and findings so far and demonstrating how we can get involved. Join us free on Tuesday 13th August at Oasis Academy, Lordshill, Southampton from 7:00pm-9:00pm to be part of the discussion!

### **August's Monthly Group Meeting: Tuesday 13th August 2019 7:00pm-9:00pm**

Oasis Academy Lordshill  
Redbridge Lane (off Romsey Road)  
Southampton  
SO16 8FA

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

# FEEDING TUBES



With regards to feeding tubes, there is a handy little website that contains key videos and supporting information on everything to do with tubes and potential feeding options.

You can dip in and out and use the website as a resource or reference tool and its helpful for family members too

Check out [mytube.mymnd.org.uk](http://mytube.mymnd.org.uk) for more information or Scan the QR Code with your Smartphone.



## COFFEE & A CATCH UP"

We'd love to see you at our Coffee Mornings if you're unable to meet us at our Monthly Meetings!

Our Coffee Support Mornings are always free, come with an abundance of warm drinks and snacks and are open to people with MND, their families, carers and professionals within the field too! There is always someone interesting to talk to and spend a few friendly hours so why not pop along to our August meet-up on Monday 19th August?

Coffee Mornings are held on the third Monday of every month at the Hazel Centre in the Countess Mountbatten Hospice, from 11:00am-12:30pm with no need to RSVP. Check out the poster on the back page for all the details.



## MUSIC FOR MND

Thank you to Alison Hughes from Nordoff-Robbins - our guest speaker at July's Group Meeting, for enlightening us to the powers of music therapy.

Enabling patients to express themselves when other forms of communication may not always be possible, music therapy offers an escape from illness and isolation. Nordoff-Robbins are the largest music therapy charity dedicated to relating through beats and melody to gain a natural response and reaction.

*" Statistics show that 92% of people in such programmes say music therapy has improved their quality of life. And we can see why!*

Members at our meeting were shown videos on how other patients have responded to Sessions and then had the opportunity to make sounds and music with instruments used at therapy groups and individual one-on-ones to get a feel of how this kind of therapy can help those with MND.

If you know someone who would benefit from music therapy please contact [Alison.Hughes@nordoff-robbins.org.uk](mailto:Alison.Hughes@nordoff-robbins.org.uk) for information on a free block of 12 Sessions!



# VOICE BANKING

Speaking of aids to help communication, our local Voice Banking Volunteer, Nicky Duffin, is looking for more people with MND to join her in preserving your own voice for future use in devices should the need ever arise.

Nicky says, *"There is a lot to take on board when an initial diagnosis of MND is received - by the individual and their family. Voice banking might be mentioned at that initial consultation and might well be hard to accept but it is a process worth thinking about and the MND Association is there to help.*

*If you would like to have more information there is plenty to be*

*found on the MND Association website and I am always happy for people to email me with any questions they may have."*

We know that MND is a rapid degenerative disease that may or may not affect vocal chords so early action is encouraged with Voice Banking. Even if you think you might not need to 'bank' your voice there is no harm in taking part in the process in a case of being 'safe rather than sorry'.

 We are very fortunate to have a Voice Banking volunteer in our region so please do use Nicky Duffin's services and help – contact Nicky at [nicoladuffinmnd@gmail.com](mailto:nicoladuffinmnd@gmail.com)



## MNDA AGM

Last month the Southampton & Winchester Group sent three representatives from our region to the Association's annual AGM. Rosemary Rockett, Jean Block and Rosie Perrett all listened to an introduction from the Chair of Trustees and speeches from CEO Sally Light and other leading specialists in MND.

Jean says, *"After a reflection on 2018, we had two of the founders of the MNDA talk about the early days of the charity and all the progress that has been made so far."*

*Rosemary and I then attended the 'Volunteers Best Practice' workshop and it was very reassuring to hear that other groups rely on '3rd party fundraising' and welcome help from student volunteers much like our Group does."*

*Rosie simultaneously attended the Research workshop that covered the importance of the MND Register and highlighted several current research studies.*

*In the afternoon session we were treated to a keynote speech by Professor Shaw who spoke about gene therapy and the glimmers of hope there is for a cure for MND."*

The day was wonderfully informative so we hope to send other members of the Group to similar Regional Conferences in Exeter and London later this year.

If you would be interested in attending and reporting back for us please do let us know!



Please send your stories and photos to [sara.alrashed12@gmail.com](mailto:sara.alrashed12@gmail.com) or pass them on to your AV.



## BOUGHTON HOUSE BASH

Our Group sent another four representatives from Southampton & Winchester to the Motor Neurone Disease Association's official 40th Anniversary celebrations at Boughton House in Northamptonshire.

The invitation for the Garden Party came to each group as a thank you for all our support and dedication to the cause over the past 40 years.

Gaby, Rosie, Jane and Margaret all recounted the day as being highly rewarding but very emotional as members re-lived their stories and struggles through the darkest times and earliest understanding of the disease.

The biggest take away from the event was the signs of hope and all the magnificent research and developments that all our awareness, fundraising and continual fighting is resulting in.

Thank you to all four ladies for representing our region and here's to more positive outcomes for MND going forward!

Don't forget that we also have our own 40th Anniversary celebrations taking place in October - look out for your personal invitations over the next few months!





## ALL ABOARD THE ALISON MCGREGOR

Last month we also held the first of our fun Alison McGregor Boat Trips.

Setting sail on Sunday 7th July, everyone aboard the especially equipped vessel witnessed the passing of four giant cruise ships and the unloading of two container ships.

Southampton always has busy waters but it was a real treat to be up so close and share the space with large crafts along the journey.

The boat houses six wheelchair spaces and welcomes family and carers to accompany those living with MND.

**Voyages are free but fill up fast so if you would like to experience a trip onboard please contact Rosemary Rockett on 023 8089 1842 ready for our Sunday 22nd September journey from Hythe Marina at 2:00pm.**



## THANK YOU!

As previously stated, we rely heavily on the generosity of others to continue helping those living with Motor Neurone Disease in our area.

It is thanks to your donations, gift aids, fundraising activities and legacies that families in need in Southampton and Winchester never have a long wait to receive essential equipment, treatment and help.

We pride ourselves on never not being able to support those that ask and we hope that continues for many years to come.

This month we would especially like to thank previous Trustee Shane Dickson for fundraising a substantial sum thanks to his golf connections.

This contribution will be added to our funds and go towards helping many others.

Thank you Shane!



mnda

motor neurone disease  
association

## ANNOUNCING ADAMA

We are delighted to announce the new Southampton & Winchester MND Group Leader Adama Luca!

After a long road searching for the ideal candidate Adama stepped into the role last month and is already making waves here and at the MedSoc Group she established at Southampton University.

Adama informs us that the Uni Group already has a Wheelchair focused fundraising lecture planned for this October and a special conference penciled in for 2020 too!

We're so excited to have Adama take up this position with us here and see these MedSoc events develop too so we'll be updating you all on those that we can join in with as well!

To quote Adama "*watch this space!*"

## ...AND FINALLY

*Just in Case Kit*

Are you aware of the 'Just Incase Kits' available through your GP?

Developed by the Association, these boxes have been designed to offer immediate relief in an emergency.

The unknown nature and unpredictable symptoms of MND can often cause stress and panic especially if you experience a sudden change, so the Association put together a kit that can be used by carers and professionals.

The box is split into these two parts that can then be filled with appropriate medications that both can use for urgent action if required.

GP's need to order the 'Just Incase Kits' from MND Connect at 0808 802 6262 and then fill the kit with medications specific to your needs before handing them over to you.

A community nurse may then train your carer on how to administer the medication.

Although MNDA hope that many people will never have to use these kits, they are available to offer peace of mind and reduce any extra anxiety people living with MND may feel.

Please contact MND Connect if you would like anymore information.

## NOTICE BOARD

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

**Next Meetings** - 13th August & 10th September

**Coffee Mornings** - 19th August & 16th September

### Other Events:

**Alison McGregor Trip** - 22nd September

**40th Anniversary Party** - 8th October

### Volunteering Roles –

Group Fundraiser

Coffee Morning Volunteers

## YOUR CONTACTS

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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

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

# **COFFEE MORNING**

**EVERY 3RD MONDAY  
OF THE MONTH -  
11.00AM**

**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](mailto:mrs_rockett@hotmail.com)

