

AWARENESS IN ACTION!



Thank you to everyone who highlighted, campaigned or mentioned Motor Neurone Disease in any way to create awareness in June.

Even though there were no official 'Awareness Month' plans, it was still superb to see everyone embracing 'Global Awareness Day' on the 21st June and continuing to raise the profile of the disease throughout the month, regardless.

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Here at the Southampton & Winchester Group we increased our presence on social media – posting daily on our facebook page <https://en-gb.facebook.com/mndsouthampton> and Twitter Handle @MNDASoton in support of Volunteers Week which was from the 1st-7th June and Carers Week from the 11th-17th June. This enabled us to connect with those we may not always see regularly and the wider MND community – allowing us to celebrate their invaluable contribution and showing how grateful we are.

We also took part in the MND Association's Thunderclap surrounding the #Scrap6Months Campaign which is encouraging England to change the law regarding people with MND not being able to access benefits quickly using the Special Rules for Terminal Illness (SRTI) as it currently only allows people who are expected to pass away within 6 months of diagnosis - which excludes unpredictable illnesses such MND.

It was also great to reach out to those that may not have heard of us before and be a part of a big movement to support those currently in this situation or may face these difficulties in the future.

The Southampton & Winchester Group also organised their own events which you can find details of later in the Newsletter, while also advertising those arranged by local fundraisers and supporters. We were astounded by your contributions during this time and thank you all from the bottom of our hearts.....

If you held your own event last month

we'd love to hear from you and share your achievements as well! Local funds raised will always go towards helping local people if handed directly to us. We love updating you all on how much of a difference your generosity makes so please do specify what area you would like your funds to go to when raising money online and redirect any JustGiving donations to the Southampton & Winchester Group so you can be a part of this too!

People with
MND
are at the
HEART
of everything we do



FUNERAL DISPLAY

A big thank you to Gaby Perrett, who is one of our devoted volunteers in Winchester, and to Chesil Street Funeral Directors for presenting a window display throughout the whole of June in support of MND.

The bright orange and blue of the charity was on display for all to see on the busy main road into and out of Winchester town centre. We know the window attracted a lot of attention so we must thank all those involved for creating so much awareness for the Association. A great job done by all!



MOTTISFONT!



Thank you to everyone who joined us at our sunny Mottisfont Afternoon Tea in June. It was a great surprise for us to see the Rose Garden being refurbished but it didn't put a dampener on our party as we repositioned ourselves on the other side and gathered guests along the way. A big thank you must also go to Rosemary and Jean for always arranging the event and being the great supporters of MND they always are!

A FULL TIPSY PIG!



Huge congratulations and well done to Ashley Morgan and son 'Grizzly' who organised an amazing fundraiser in June with the help of the landlord at the Topsy Pig Pub in Romsey.

Many of you may remember us promoting the 'Grizzly Pig Fest' in the last Newsletter – a day jam- packed full of music, food and games so we hope all those that attended the shindig had a joyous day out!



4 volunteers from MND also attended the event to help with the selling of raffle tickets as there were a number of amazing prizes to give away.

While waiting for the Raffle to be called guests were entertained by various local musicians and food was provided by a BBQ in the pub garden.

With new and old faces popping in and out - everyone reported back what a wonderful time they had which makes the final amount raised, £458.72, even sweeter!

Well done guys and thank you to all our volunteers on the day too!



BOAT TRIPS BON VOYAGE

Our ever-popular 'Alison McGregor' Summer boat trips are now in full swing, with June's voyage not leaving a spare seat.

With the delightful weather we have been experiencing, sailing up the Solent provides even better views so we expect our next two events to be in high demand. This is a free trip for people living with MND so if you would like to hop aboard on either Sunday 12th August or Sunday 2nd September, please reserve your place by contacting Rosemary Rockett on 023 8089 1842. Spaces for carers/family members are available too.

TALKING HEADS TALKS A LOT OF CASH!

Once again Aaron Vincent welcomed us all into the Talking Heads music venue for a night of music and fundraising. On Saturday 14th July, local bands showcased their latest tunes to a full house as guests paid £5 a ticket for an evening jam packed with entertainment. Aaron updates us that the event was another success with them finishing the night with standing room only! This led to a great total at the end of the evening too as The Talking Heads counted £850 to donate to the Southampton & Winchester Group. Thank you to everyone who attended and an even bigger thanks to Aaron for his continual support of MNDA.



THANK YOU'S!

Along with all the great fundraising events mentioned above, the Southampton & Winchester Group also received generous donations to add to the pot as well Firstly, thank you to the Twyford Social Club for displaying a MNDA Collection box on your premises. £38.14 was counted in loose change and goes to prove that every little helps. If you know of another place one of our MNDA Collection boxes could

be displayed please get in touch as every penny goes towards helping local people. Thank you also for donations from family and friends of people with MND that have recently passed away. We are so grateful for all our donations but especially of those that are given to us through difficult times. Thank you for thinking of us and donating in tribute. We continue to fight in your name.

COFFEE & SUPPORT

A big hello and welcome to everyone who has been joining us at our Coffee Mornings over the past few months - we love catching up with you all and would love to see even more of you join us! Please pop along to our next events on Monday 20th August and Monday 17th September at The Hazel Centre, Countess Mountbatten Hospice from 11:00am-12:30pm whether it is your first time or fiftieth! We'll be waiting with a cuppa and a warm welcome! Please see the Poster for more information.

GROUP MEETINGS

We've been treated to some outstanding Speakers at The Southampton & Winchester Group Meetings lately. Last month we were visited by MNDA Care Centre co-ordinators Claire and Nadine who joined us from Southampton General Hospital to inform us about their roles at the Centre and what they hope to achieve going forward. We know many people living with MND in our area may pass through the Southampton Care Centre at some point so it is important for us and our AV's to get a good idea on the services you and

Motor Neurone Disease Association Southampton & Winchester Group



Coffee Mornings

Place

The Hazel Centre
Countess Mountbatten Hospice
West End
Southampton
SO30 3JB

Time

11am to 12.30pm

Date

Every 3rd Monday
of the month

For more details or assistance with travel taxi costs
please contact Rosemary Rockett on 02380 891842
or email mrs_rockett@hotmail.com

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Northampton NN1 3FR
Tel: 01604 250605
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Registered Charity No. 294234



your families receive and your experiences while doing so.

The MND Care Centre is continually evolving as we identify gaps or improvements that can be made. This is mostly thanks to feedback the Centre receives from families, carers and supporters which is again something that is constantly encouraged. If you missed out on having your say or think of something you want to ask/have a problem with in the future please contact the team at uhs.southamptonmndcarecentre@nhs.net For August's Group meeting we will be treated once again to Professor Karen Morrison speaking about her work in MND research and her hopes and plans for the future. If you would like to attend, hear her talk or put a question to the Professor, please feel free to come along from 7:00pm-9:00pm at The Rose Road Bradbury Centre, Aldermoor Road, Southampton SO16 5NA on Tuesday 14th August. Alternatively send in your questions and we will put them to Professor Karen on your behalf.

COMMUNITY AIDS FUND ...

We are thrilled to report that there is now an official 'Community Aids Fund' for our region that will allow people living with MND access to a big hold of useful equipment that can be loaned out and shared. This will hopefully reduce wait times for certain items and provide a stockpile that people in our area can benefit from. Please contact your AV or Louise Rickenbach for more information. Nicky Duffin, our local Voice Banking Volunteer (VBV) also provides all equipment needed for the Voice Banking

process and can assist you in the set up and operation. Nicky provides a great opportunity to anyone concerned about losing their voice - and as one of only a handful of regions to have a VBV, we are extremely lucky to have her.

If your needs are a little bigger please do still contact the local Group. Since the last Newsletter we have been able to provide a powered wheelchair, partly fund a stair lift and contribute towards housing modifications for people living with MND in our area.

ADVERTISE EQUIPMENT

Speaking of helpful equipment and aids, if you have any items that you would like to pass on or sell that you think may be of use to someone living with MND, please get in touch and we will advertise for you on our social media platforms and in this Newsletter.

We know equipment needs can sometimes be very specific and individual but there may be someone in a similar situation to you that may be requiring an item you possess. Please let us know and we will do our best to put you in touch.

Please note – all transactions/deliveries will need to be arranged personally and the Southampton & Winchester Group do not hold equipment checks on any items. It is your responsibility to take all necessary measures when selling or buying items.

HEADS UP COLLAR!

After seeing many people with MND struggle with weakness in their neck we are delighted to pass on news of the

launch of a brand new support brace called 'Heads Up'

The collar, which has been in research and development for several years, was firstly tested on 150 people living with MND to judge if the design held merit and provided appropriate support and comfort. After a month of trialling the 'Heads Up' Collar, 80% of people requested to keep using the new design to help in every day tasks such as eating and reading and many remarked on its 'life-changing' capabilities.

Many people with neck weakness have found their quality of life improve while using the collar, giving them more independence too.

The collar's support can be controlled depending on need and deals with many of the issues identified as a problem in previous neck brace and support designs. The Research Team at the University of Sheffield along with TalarMade (who produce the collar) are over the moon at its effectiveness and it is now available through the NHS or direct from TalarMade.co.uk. Contact your MND Care Centre or GP for more information regarding the 'Heads Up Collar'.

FAREWELL OUR FRIEND



It is with great sadness that we waved farewell to one of our long standing and dedicated MND supporters as she stepped down from her role recently. Sue Harding has primarily been the Secretary of the Southampton & Winchester Group for many years (as well as stepping into other roles when needed) so it is a great loss to our Group that we will no longer have her input and expertise on a daily basis.

Sue has however said she will remain a supporter of the Association so we hope to see her popping up at local events and at our end of year Christmas Party. She said, "It has been a pleasure to be a part of the Group for the past eight years. Thank you to everyone for your friendship during this time – and I will see you all again soon!" We'd like to send Sue our very best wishes for the future and thank her once again for everything she has done in contributing to the local Group. We'll miss you Sue!

FUTURE EVENTS



The S&W MND Group will once again be taking part in the Winchester Car Boot Sale at the Cattle Market on Sunday 30th September.

If you would like to contribute to our haul, volunteer on the day or hold your own Car Boot Sale at the event and donate a percentage of your takings to the local Group - please contact Gaby Perrett at fandgperrett@hotmail.com for more information.

NOTICE BOARD

Group/ Open Meetings
(Second Tuesday of each month)
The Rose Road Association
Bradbury Centre
Aldermoor Road
Southampton
SO16 5NA 7:00pm-9:00pm

Next Meetings
14th August &
11th September

Coffee Mornings
20th August & 17th September

Other Events
Winchester Car Boot Sale
30th September

Volunteering Roles
Group Leader
Association Visitors
Coffee Morning Volunteers

Position	Name	Phone	Email
Group Contact/AV Co-ordinator	Rosemary Rockett	023 8089 1842	mrs_rockett@hotmail.com
Group Fundraiser	Lyndsy Ambler		l.j.ambler@live.co.uk
Banker of Donations	Rosie Perrett		rosie.perrett@googlemail.com
Newsletter Editor	Sara Al-Rashed		sara.alrashed12@gmail.com
RDCA	Louise Rickenbach	03453751831	louise.rickenbach@mndassociation.org
Regional Fundraiser	Pamela Fry	07918 652201	pamela.fry@mndassociation.org
Volunteering Development Coordinator	Claire Tuckett	07831 349382	claire.tuckett@mndassociation.org

Group Websites

<http://mndsoton-winch.org.uk>



www.facebook.com/mndsouthampton



Twitter - @MNDASoton

www.justgiving.com/mndasouthampton

MND Connect – 0808 802 6262 Charity No. 294354