motor neurone disease association

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

Southampton & Winchester Group

August 2022

All the latest MNDA news from the local area

Global Awareness Day

page 4

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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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A TRIBUTE TO OUR ANDY

We were all saddened to hear that our friend Andy Cadwell passed away in June.

Andy was first diagnosed with Motor Neurone Disease seven years ago and during that time tirelessly campaigned for the charity and awareness of the illness, while holding the role of Trustee and being an invaluable member of the board.

Here at the Southampton & Winchester Group, we were lucky to get to know Andy and his family when they moved into the area and became a part of our MND family.

It is testament to Andy's personal insight and experiences of MND that we recently discovered that he secured enough votes to be re-elected as a Trustee.

We know he would have been proud to hold the position again and will be missed terribly by all who knew and worked with him.

All our love goes to Andy's wife Jeannie and their daughter who has set up a wonderful JustGiving page for MNDA in tribute to her father. Please take a look here:
https://www.justgiving.com/fundraising/mnd-warrior

JUNE’S MND AWARENESS MONTH

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Thank you to everyone who supported us on Global Awareness Day on the 21st June and all those who lead conversations, campaigns and fundraising throughout the whole month to help build the disease’s profile within the public arena.

A big thanks goes to Dawn Pond, Southampton City Council and the Guildhall who were all fundamental in organising a big light up of the Southampton monument on the evening of the 21st.
Shining bright in MNDA’s blue and orange, onlookers were able to see Southampton Guildhall lit up differently in support - and hopefully create more awareness in the process.

Did you do something special for Global Awareness Day? Let us know by getting in touch.

THANK YOU VOLUNTEERS & CARERS

Heart

People with MND, their families and carers are at the heart of everything we do.

Collaborate

We collaborate and value everyone’s contribution.

Openness

We achieve our aims through building open and transparent relationships.

Commitment

We achieve excellence through personal commitment and ongoing improvement.

Respect

We respect and respond to people’s diverse needs, backgrounds and views.

As you may remember, to coincide with Awareness Month - Volunteers and Carers week are held in consecutive weeks at the beginning of June.

Our MNDA volunteers and carers are the glue that holds our Association together and we would not be able to function as we do without their dedicated and heartfelt support.

We hope that we were able to thank everyone at the Southampton & Winchester Group who gives their time and care to those living with Motor Neurone Disease in June. Please know how valued you are everyday!

Matthew Cobble, Head of Volunteering at the MND Association also has a special message for you all, "I wanted to take this opportunity to say a huge thank you for the vital work you do as volunteers to support people living with and affected by MND.

Every day I hear new and inspiring stories of courage, creativity, commitment, and kindness from our volunteer community.

All of the actions you take and the time you give are helping us beat MND together.

Thank you for all you have done and continue to do for the MND Association."

Thank you once again to all our local carers and volunteers!

TEA FOR (MORE THAN) TWO!

It sounds like our Afternoon Tea event at the Sir Harold Hillier Garden Centre was a great success.

Ruth who attended the get together with her husband Terry said, "The rain stayed away thankfully and everyone had a good time.

Some of us even arrived early to have lunch in the restaurant before wandering in the gardens and meeting up with the group.

Rosemary and Jean then kept us plied with scrummy cakes and biscuits with lots of tea and coffee too."

If you would like to attend an event similar to this, why not pop along to one of our Support Coffee Mornings?

Held on the third Monday of every month, people living with MND, their family, friends and carers are all invited to join in with the chat over a good cuppa!

Check out our Noticeboard for more details!

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ALISON MacGREGOR boat trip

2pm - 4pm

That's one trip down and two more to go! We hope everyone who boarded the Alison MacGregor boat on the 30th June had just as great a time as fellow sailor Rosemary,

"The weather was really good and as the tide was high we were able to get right up the Itchen.

I have been on the trip before but have never got up so far and it was also a nice change to be on a working day instead of a Sunday as we were able to see some of the workings going on at the dock."

The journey is different every time the boat travels along the Solent so please do join us on one of the other FREE trips we have planned this Summer.

The boat is able to accommodate six wheelchairs with a family member, friend or carer and will leave from Hythe Marina on;

Tuesday 23rd August
2:00pm-4:00pm

Sunday 18th September
2:00pm-4:00pm

To book your place please contact Rosemary Rockett on 02380 891842 with the date you would prefer.

NATIONAL BAME HEALTH & CARE AWARDS

A huge well done to our former Group Leader Adama who was honoured at a special ceremony in London after being shortlisted for a BAME Health & Care Award.

Adama attended the event with Area Support Coordinator, Dawn Pond – who nominated Adama, and both we able to soak in the atmosphere and hear about all the other nominees hard work.

Although unlucky in securing the top spot this time, it was wonderful for Adama to be recognised.

We were all rooting for you Adama and appreciate all you have done for the Southampton & Winchester Group and local people living with MND. Thank you!

POUNDING THE PAVEMENTS

A massive well done and thank you to both Emma and Rebecca, who have been training hard to complete the Draycote 10k Race and Blenheim Palace Triathlon, respectively - in memory of George Perrett.

Both runners raised over £1,000 altogether through their JustGiving pages, which has now been sent to Head Office to support people around the country living with MND as well as research into treatments and ultimately a cure.

It is vital that we continue our fight to find a cure for MND so in the future no family has to go through the loss of losing a loved one to this devastating illness.

Thanks to wonderful supporters like Emma and Rebecca, we get closer to that goal everyday.

Thank you to everyone who sponsored Emma and Rebecca, if you would like to visit their JustGiving pages they can be found here;

Emma: Top QR Code:
https://www.justgiving.com/fundraising/emma-lewis87
Rebecca: Bottom QR Code:
https://www.justgiving.com/fundraising/rebecca-perrett5

MONTHLY MEETINGS

Did you know that we meet regularly each month to discuss current issues, catch up and host specialist speakers?

All our events are free and a great way to meet like-minded people, make friends and get advice and information.

As well as our Support Coffee Mornings previously mentioned, we also hold a Monthly Meeting on the second Tuesday of every month at Oasis Academy Lordshill, Southampton.

Last month we were joined by Stephanie from the Respiratory Team, who gave us an insight into the teams workload covering over 400 patients in Hampshire and Dorset and the tests those patients undergo to assess their respiratory needs.

Stephanie was able to give us lots of helpful demonstrations on a non-invasive ventilator and talk about cough assist machines.

She also mentioned how some medical equipment can be recycled as teaching aids, which got us thinking....

If anyone has any old masks etc that they do not use please could you let your AV know?

Many people test equipment to find the right fit and this cannot be reused on another patient so they sit at the back of a cupboard or get thrown away.

In an effort to be less wasteful and more sustainable, these can be used for teaching instead and benefit others in the future.

If you have any questions relating to respiratory issues please talk to your consultant, GP and AV.

People living with MND in our region have expressed how helpful their appointments are at the Unit over other resources so we highly recommend this route if you are experiencing any problems.

At August’s Monthly Meeting we will be joined by a different speaker so please do join us at Oasis on Tuesday 9th.

The venue is fully accessible and everyone is welcome!

EMERGENCY GRANT EXTENSION

We are happy to announce that the Association's 'Emergency Grant' has received another deadline extension so people living with MND will be able to submit an application up until the 31st December 2022.

Originally set up to help cover financial difficulties caused by the COVID-19 pandemic, the Association now recognises the cost of living crisis and the potential further need for monetary assistance as we enter into winter and increasing hardship.

Families and individuals living with the disease can find household expenses escalate due to many factors and the current climate may make those costs feel unmanageable.

Please do not suffer in silence, speak to your AV, Support Services or look at the MNDA website for help with claiming benefits.

To apply for the Emergency Grant please fill out this form https://www.mndassociation.org/support-and-information/our-services/financial-support-information-for-people-with-mnd/?dm_i=40VS,1FI0O,2S9FU2,589KJ,1

Or call the Support Services team on 0808 802 6262 if you have any questions.

COULD YOU BE A STAR?

The casting team behind mega hit films 'Fantastic Beasts' and 'Judy' are currently looking for someone to play the lead role of Peter Scott-Morgan, in a film about his life.
The team at Fiona Weir Casting Ltd welcome applications from actors living with MND to portray Peter, who lived with Motor Neurone Disease as he transitioned into becoming the world's first human cyborg and to fulfil supporting roles of people also living with MND.

Applications are open to all ages, genders and ethnicities. If you or someone you know is interested, please email peterfilmfwc@gmail.com and provide

- Your email address
- Your postal address
- Your telephone number.

You will then receive instructions on how to create and send an audition tape. Fiona Weir Casting Ltd aim to make the audition process as accessible as possible, so please let them know if you want to receive or send information in an alternative format.

Good luck to everyone auditioning – we can't wait to see this story told on the big screen!

NOTICE BOARD

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

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

STAY SAFE. CONTINUE TO FOLLOW GOVERNMENT RULES.

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

YOUR CONTACTS

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W: justgiving.com/mndasouthampton
Facebook: facebook.com/mndsouthampton
Twitter: @MNDASoton
MND Connect **T:** 0808 802 6262
Registered Charity No. 294354

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Do you enjoy listening to people?

Volunteer

Help someone in your local area

Are you a warm and caring person? Want to help in your community? We are seeking volunteers to join our friendly local team giving support to individuals and families affected by Motor Neurone Disease.

You could train to be a Visitor, help at local get togethers or champion the needs of people affected by MND. You'll be helping to make a real difference.

To find out more
Email: volunteering@mndassociation.org
Phone: 0345 6044 150

MND Association   @mndvolunteering

www.mndassociation.org
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