



Motor Neurone Disease Association

East Sussex Branch Newsletter

September 2024

SAVE THE DATE – TUESDAY 10 DECEMBER

A few months ago I was approached by Anthony who was keen to run a fundraising Comedy Night for us. This idea really excited me as it's something completely different and something we had never thought about before. But trying to find a venue at the right price (free!) proved far more difficult than we had thought.

Then by chance I met with Patricia, Fundraising and Marketing Manager at The Chaseley Trust in Eastbourne. Chaseley is one of only five nursing homes in England that specialises in complex neuro-disabilities including brain injury, stroke, spinal cord injury, and degenerative neurological conditions including MND. Patricia and I discussed the possibility of joint fundraising and having visited the home, I discovered a room that I thought would be suitable for a comedy night. Not only is there a room but it has an adjacent bar – even better! Anthony visited Chaseley and agreed that the venue would be perfect so we are now going ahead and organising the night which we hope will be the first of many.



It's very early days but I wanted to give you plenty of notice so you can spread the word amongst family and friends. Once we are more organised we will set up an on line booking system and tickets will be charged at just £15 each. The bar will open at 6 pm and the show will run from 7 pm to approximately 9 pm.

As there will be a small number of costs involved, we need to find sponsors. Can you help? Do you have contacts at any of the local (Eastbourne) businesses who we could approach to help us? If you can help, please contact me by email: sharon.bass@mndassociation.org or telephone 07484 657310.

I'm really excited about this project. I'm sure it will be great fun and hopefully will raise a worthwhile amount for both Chaseley and MND (East Sussex Branch). So save the date, **Tuesday 10 December**, let me know if you have any business contacts - and wait for further information!



Sharon



FUNDRAISING

MND AWARENESS DAY 21 JUNE

Within the East Sussex Healthcare Trust (ESHT) Planned Care Division we have 3 MND Coordinators, with Simon Wilson covering Lewes, High Weald and Havens, Vicky Lester covering Eastbourne and Natasha Sinden covering Hastings. They lead a monthly MDT Forum on each site to coordinate the MDT involved in the care of this complex group of patients.

For MND Awareness Day the ESHT Neurophysiotherapy Outpatient Team organised 3 linked fundraising events. Dawn Ivan-Clancy, Specialist Neurophysiotherapist and Lisa Cole Neuro PTA arranged a cake sale, quiz and a 'guess the number of sweets in a jar' – the 2 events raised £265 for the East Sussex MNDA. Poonam Yadav (Admin Support) and Debbie Soave (Specialist Neurophysiotherapist) signed up for the St Wilfreds Hospice 30 mile Wilf Walk on Sat 22 June and raised £859.

We would like to say a huge thank you to colleagues at Conquest and Eastbourne District General Hospital who supported us with bringing in cakes and donating to/sponsoring us for the 3 events.

Tash

Natasha Sinden | MND Specialist Practitioner

Raising money for MND is so easy while you shop online!

Did you know that whenever you buy anything online via the easyfundraising.com website, you could be raising a free donation for Motor Neurone Disease Association - East Sussex Branch?

There are over 4,400 retailers including John Lewis & Partners, M & S, supermarkets, Argos, Uswitch, eBay, Just Eat, Now TV, Domino's Pizza and Audible ready to give a free donation every time you shop online via easyfundraising. It only takes two minutes to sign up. Plus, if you sign up and raise £5 in donations, easyfundraising will give us a bonus £5 donation.

All you have to do is:

1. Go to this website address:
www.easyfundraising.org.uk/causes/mndaeastsussexbranch/?invite=4B71JT&referral-campaign=c2s&utm_campaign=raise-more&utm_medium=email&utm_content=raf-e
2. Click 'support this cause' and create an account
3. Choose from over 4,400 retailers to do your online shopping as normal and our cause will receive a free donation with every purchase you make.

GET YOUR CHRISTMAS CARDS NOW

It may only be September but it's never too early to start planning and the MND Facilities Team has been hard at work handpicking this year's range of cards for the festive season. All cards are available to view and purchase on the MND Association's website. Got to www.mndassociation.org and click on shop with us.

Alternatively, you may like to consider sending us a donation in lieu of giving Christmas cards this year. Just go to our

branch website www.mndaeastsussex.org.uk and click on any of the

JustGiving

logos. Or contact us

for our bank details (Treasurer – 07913 891525). Your support is so much appreciated.



THE LOVE INSIDE shortlisted for awards

We are delighted to share with you that our first television advertising campaign in a decade, *The Love Inside*, has been nominated twice at this year's Third Sector Awards.

The campaign is shortlisted in the categories for *Best Large Charity Film* and *Communications Campaign of the Year* and the awards recognised the association alongside our agencies, GOOD and MI Media. The award winners will be announced at a ceremony on Friday 20 September.

Our Director of Engagement, Richard Evans, said "The Love inside is a powerful campaign which shows the devastating impact MND has on so many people. While *the Coronation Street* storyline may be fictional, for too many people Paul's story is very real, something we were keen to capture, with the support of all those involved.

"It's really important to remember it would never have been possible without Mike and Zoe, Louise, Rob and Mike and their families and we are incredibly grateful to them for everything they have done to support us.

"While we celebrate the success of the campaign, we also remember Louise and Mike who sadly died before the campaign was broadcast. Their loss is a stark reminder of the cruelty of MND and the work we now must do".

With the support of his family, the campaign will continue with Mike's story taking centre stage. The advert will focus on his connection with Alli Anthony, who was his Area Support Co-ordinator, and how the Association was able to support him and his family. Once again, the adverts will coincide with the developing *Coronation Street* storyline, featuring in the ad breaks of popular daytime programmes including *Loose Women*, to raise awareness and vital funds.

WINTER FUEL PAYMENTS - letter to the Chancellor

Our Chief Executive, Tanya Curry, has written to the Chancellor of the Exchequer to outline our concerns about the recent decision to restrict Winter Fuel Payments to people receiving means-tested benefits and the impact this will have on people living with MND.

We are urging the Chancellor to meet with us and members of the MND community so we can explain the impact this decision will have on people with MND.

We will continue to work constructively to raise this issue with the government and to seek a solution to protect people living with MND from the impact of this decision.

WE ARE ONLINE! Visit the East Sussex MNDA East Sussex branch website at www.mndaeastsussex.org.uk

You can also find us
on Facebook @MNDAAEastSussex and Twitter @MNDAAEastSussex



THE BRANCH NEEDS HELP!

The committee of the East Sussex Branch is very small, just 5 of us so we could really do with another member or two. Can you help or do you know of anyone who would like to join us? We meet every couple of months on Zoom on a Wednesday evening and we manage to get through our meetings as quickly as possible! Between meetings we communicate via email so any issues arising can be dealt with quickly and efficiently.

We have a Minutes Secretary but really need someone to take on the rest of the secretarial role. We need someone who is organized and has knowledge of Word and Excel together with an understanding of databases. Ellie puts together our newsletter but there are times (such as now) when she isn't able to help us and on those occasions it would be great if the Secretary could help compiling the newsletter.

We also need general help on the committee taking on roles and tasks as they arise.

If you can help, or know of someone who can, please contact :

Sharon Bass at email: sharon.bass@mndassociation.org.

We would like to have contact with businesses and clubs across the East Sussex area. Do you have any contacts who would perhaps put on a fundraising event, provide a raffle prize or even just give us a donation?

Some companies operate "Matched Giving" whereby if an employee does some fundraising, the company will match the amount raised. A really great way to help us. Do you work/know of any such company?

Any information you can provide would be really helpful. Contact Sharon Bass :

Email: sharon.bass@mndassociation.org or telephone 07484 657310.

If you do not wish to receive this newsletter please let me know:

sharon.bass@mndassociation.org or telephone 07484 657310.

We try to keep our costs to a minimum and therefore prefer to email our newsletters. Therefore, if you have received this newsletter by post and have an email address that we could use in future, do please let me know : sharon.bass@mndassociation.org.

If you have any comments, stories or articles for our quarterly newsletter, please email them to Ellie Seymour: hello@wordsbyellieseymour.com

