



motor neurone disease
association

West Sussex North

July 2021 Newsletter

London to Brighton Run

In aid of a special teacher

In Easter 2020, Loxwood School teacher, Lindsay Webber, received the diagnosis that she had MND. As a teacher, she had supported and got Fanny Newman's eldest daughter ready for secondary school and was geared up to do the same for Fanny's other daughter in the following academic year.

After hearing the sad news about the beloved teacher of her daughters, Fanny decided to really challenge her running skills and raise funds for our branch.

Fanny signed up for the first half of the London to Brighton race, which took place in May. With an initial target of running 56km and a fundraising target of £1,500, she beat both of them fantastically. With the help of a £1k donation from Lindsay's parents, the fundraising total currently stands at £2,746 from 60 supporters. Fanny also ran a hugely impressive 57km in just over 7 and a half hours.

Fanny said "Lindsay is an inspiration, a fantastic human being and the best teacher my daughter has had. And for that, I will always be grateful."



In this issue:

Brighton Walk fundraiser

Long-service awards for Chris Sheridan and Julie Taghan



Brighton Seafront Walk for MND

Sunday 29 August, from 2pm

A joint fundraising walk between West Sussex North, West Sussex South and East Sussex, should prove an excellent opportunity to get together safely, enjoy the sunshine and raise some much needed funds for all our local branches.

The walk is a round trip starting at the Big Beach Café, Hove Lagoon BN3 4LX and then walking the 2 miles to the i360/West Pier Brighton and back again.

You'll have the chance to take in the beautiful, peaceful sights of Hove Lagoon. A public park with boating lake, watersports, grassland and seafront views.

If you've not had a chance to watch the i360 ascend and descend, then this is your chance. There is equally something majestic about the ruined West Pier.

We'd love you to join us for our first ever inter-branch walk along the Brighton seafront - a simple walk wearing

MND T-shirts or something blue and/or orange.

The seafront is flat and therefore easily accessible for wheelchairs, children, dogs etc. so please come along for either a 4-mile round trip or 2 miles one way.

If you want to join us, please contact Julie by email: julie@mndwestsussexnorth.com or mobile: 07709 425957 so that we can let you know should there be a change of plan.

If you want to donate visit, <https://www.justgiving.com/fundraising/mndsussexwalk> or use the QR code above to donate.

Here's to a fun and sunny afternoon together.

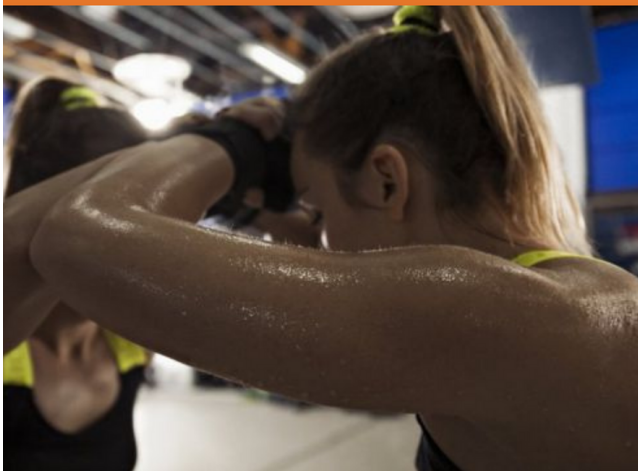
Send a text and make a difference to someone local living with MND

You can now send a donation direct to the West Sussex North Branch via text

Text MND4WSN to 70085. It's that quick and easy to do.



SCRAP6MONTHS



National News Update: Scrap6Months campaign victory!

And research into link between physical exercise and update on United to End MND campaign

It's brilliant to be able to say the Scrap6Months campaign has been victorious across the UK!

The campaign, in partnership with Marie Curie, started three years ago to scrap the unfair rule that someone with a terminal illness has to prove they have 6 months or less to live in order to access fast-tracked benefits.

On 8 July, the UK Government pledged to make it easier for people with a terminal illness to claim benefits using the Special Rules for Terminal Illness and be able to access the fast-track system to claim.

Sally Light, CEO of the MND Association said: "This is a victory for the hundreds of campaigners across the country who have worked tirelessly alongside the MND

Association for three years... we believe that if the rules change as proposed the vast majority of people with MND should be able to access the Special Rules.

"Now the recommendations must be implemented quickly to ensure no more people, already facing the most difficult time of their life, have to suffer the indignity of a long drawn out process."

In other news, many of you will have seen the news about the recent research that has identified a link between regular, physical and strenuous exercise and MND, for those who are genetically at risk of the disease.

Co-author of the study, Dr Johnathan Cooper-Knock from the University of

Sheffield Neuroscience Institute said: "Complex diseases such as MND are caused by an interaction between genetics and the environment. We urgently need to understand this interaction in order to discover pioneering therapies and preventative strategies.

"We know that most people who undertake vigorous exercise do not develop MND. Sport has a large number of health benefits."

The question of whether exercise causes or contributes towards MND is still very much unanswered.

Finally, the United to End MND research petition has closed with 110,700 signatures. The petition will now be debated in Westminster. Thank you to everyone who supported this.

Get the Online Retailers You Use to Donate via EasyFundraising

Have you tried raising funds for us yet by doing your existing online shopping through EasyFundraising?

It's safe, easy and generates funds for the branch from your existing online shopping – with no extra cost to yourselves. It simply gets the retailers you are purchasing from to donate to us. So why not give it a try and help do that little bit extra to support the branch?

So far just over £160 has been raised but given how simple and convenient it is, we are urging all of our branch supporters to use it.

There are over 4,000 shops and sites on EasyFundraising ready to make a donation – such as eBay, Argos, John Lewis, Booking.com and Marks & Spencers. It doesn't cost you any more as it's the retailers who donate as a result of you purchasing from them via EasyFundraising.

All you need to do is:

1. Go to
https://www.easyfundraising.org.uk/causes/mndawestsussexnorth/?utm_campaign=raise-more
and join for free.
2. Every time you shop online, go to EasyFundraising first, find the retailer or site you want and click through from here. Then shop just as you usually would!
3. After you've checked out, the retailer will make a donation to Motor



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There are no catches or hidden charges and the branch will be really grateful for your donations.

Thank you for your support.



Long Service Awards

For Julie Taghan and Chris Sheridan

The branch has given out not one, but two Long Service Awards recently. Firstly to Julie Taghan, Branch Chair for 5 years! And secondly, to the amazing Chris Sheridan, AV, Vice-Chair and so much more to the branch, for 15 years volunteering. Huge congratulations and thank you to you both.

Chris had this to say: "I have been privileged to meet many inspirational people, albeit at a very difficult time in their lives. The challenges faced by those diagnosed with MND and their families are enormous and have of course been magnified during the Covid pandemic. I'm full of admiration for all affected by this devastating disease, and any support that a visitor is able to give is truly rewarding."



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