



Our Branch is the chosen charity for two organisations

It is our great pleasure to announce that we are the chosen charity for not one, but two organisations this coming year!

From our previous experience of these types of arrangements, it is a real privilege to have been chosen and a fantastic source of funds to enable the Branch to continue to support patients with MND, carers and their families.

The first organisation is West Sussex County Short Mat Bowls Association. We have been nominated, alongside one other charity – Ca-

nine Partners, as the recipients of funds from the annual Short Mat Charity Fours Competition. The event will be held on March 19th. The Branch was chosen due to a member of the Association, a keen and passionate bowler, who was sadly diagnosed with MND. The Association saw the experience first-hand of patients diagnosed with MND and the impact on their loved ones.

London Road Methodist Church, in Horsham, are the other organisation that has kindly selected our Branch as one of their three cho-

sen charities for the year: one local, one national and one international. Each of us will receive the funds from four collections taken after services of Holy Communion at the start of each month. Additionally, supporters of a particular charity may arrange fundraising events etc.

We thank them for their support and will keep everyone posted on the funds raised, and the difference they make to our work.

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A day in the life of...

our new MND Practitioner: Hennie Sleeman



Hello, I'm Hennie.

I qualified as an Occupational Therapist (OT) in 1992, and have worked since then in West Sussex starting at Worthing and Southlands Hospitals. In 2003, after a 5-year career break while my children were small, I joined the specialist Community Neuro Rehab Team based in Worthing and became the Lead OT for the Team in 2008.

The other part of my background is that I have been on the other side of an MND diagnosis: I lost my Dad to MND in 2016, here in Horsham, supported by the very services I'm now a part of.

What drew you to becoming an MND nurse now?

I've worked with people with MND throughout my time with the Neuro Team and have developed a special interest in this area of work. In the winter of 2020/21, I helped to cover this job one day a week, so when the vacancy came up it felt like a natural progression to apply.

What are you finding most rewarding about your new position?

What I love most, and always have, is meeting people – my "patients" and their families – all with different stories, experiences and ambitions. MND gives me the privilege of being able to get to know them over a relatively long period. If in that time I can make a positive difference and help them get the right services, equipment and support at the right time, then that is hugely rewarding.

What does a regular day look like for you as an MND Practitioner?

There's no such thing as a regular day – they're all different! Most days I visit between one and three people at home to review their MND, answer queries, advise about any changes, and generally provide support. Each visit may lead to provision of information, onward referral to other services, liaison with professional colleagues to update them, a letter to a GP and more. Alongside this my work involves responding to emails and phone calls, attending meetings, participating in research, mentoring students and getting together with colleagues for peer supervision.

There are three parts to my day-to-day job which make up the best parts of my day.

Firstly, working in collaboration with a wide range of professional and MND Association colleagues. Managing MND is a team effort!

Secondly, it's seeing patients do well - managing the tricky juggling act of planning ahead while still making the most of life here and now.

Finally, not commuting to Worthing every day and being able to cycle to some of my local visits!

There just isn't enough time in the day to get everything I want done.

What do you enjoy doing in your spare time?

My husband and I enjoy walking on the South Downs and exploring the UK on holiday. I also love gardening and growing my own veggies, and going to the cinema.

We have two adult children – a son and a daughter – with whom we love spending time; our son is getting married next year so there is a wedding to plan!

Can you tell us one surprising thing about yourself that people wouldn't expect?

I spent 9 months living and working on a 500,000 acre sheep station in Western Australia where our nearest neighbour lived 40 miles away. I can ride a motorbike and learnt to navigate in the bush by the sun. (My original training was in agriculture).

Brighton Seafront Walk fundraising success and it's happening again this year!

Last summer may be a dim and distant memory for some, but for many of us there was a stand out highlight – the Brighton Seafront Walk in partnership with West Sussex South and East Sussex Branches.

Around 80 people came along and the weather could not have been better for us! Sunshine and warm. It was the perfect weather for a great walk. Everyone enjoyed it immensely and got to take in the sights of Hove Lagoon, i360 and the West Pier.

A phenomenal total of **£4,301.06** was raised which will be split between the three branches, £860 of that was raised on the day through bucket collections. A truly amazing effort!

Very importantly, we need you to save the date for this year's seafront walk: **Saturday 13th August**. Looking forward to it already!



Easy ways to fundraise for us!

Four easy ways to help us support those living with MND locally...with over £1,000 having been raised already!



1. Easy Fundraising

Over £160 has been generated for the Branch, simply by people starting their online shopping at www.easyFundraising.org.uk/mndawestsussexnorth. With over 4,000 online retailers signed up, simply register for free, click through to the retailer and make your purchase as normal. No extra costs to you, but the retailer makes a donation to us!



2. Giving Lottery

Want to have a chance to £25k? Then go to www.givinglottery.org.uk/support/mnda-west-sussex-north-branch and buy your tickets. 60% of the ticket sales will come to the Branch, and every ticket has a 1 in 50 chance of winning a prize every week. Nearly £400 has been generated for us already.



3. Recycle for Good Causes

Using a network of experts to resell your donated items with the proceeds going to our Branch. You can recycle anything from old cameras, jewellery, currency and stamps, game consoles, laptops, mobile phones and tablets. For more information about visit: www.recyclingforgoodcauses.org.

4. Donate direct!

Simply text MND4WSN to 70085 to donate £5 (texts cost £5 plus your standard network charge). To donate more, simply add the number to the end of the text e.g. £20 = MND4WSN20

Or visit <https://www.justgiving.com/fundraising/westsussexnorth>

Horsham Street Collection is a go!

Our first street collection since the pandemic is happening on **Saturday 30th July** in Horsham. It's previously been one of our most successful fundraising

activities and we hope it will be again. We are looking for volunteers! Please email us to take part: julie@mndwestsussexnorth.com



£50 million for MND Research!

National News



In November 2021 the government announced an investment of £50 million, over 5 years, dedicated to researching MND.

After two years of campaigning, we did it!

It was a great team effort by the MND Association, MND Scotland, My Name's Doddie Foundation, people with MND, their friends and family, and neurologists up and down the country.

Meetings are being arranged with Ministers to confirm when and how the funds will be made available.

Branch Socials

We can't wait to be getting our in-person socials back in the diaries!

They will be taking place at The Ark Community Centre, Turners Hill, 3pm - 5pm:

- Sunday 24th April
- Sunday 26th June
- Sunday 21st August
- Sunday 9th October
- Sunday 4th December

Put the dates in your diary and we look forward to seeing you.

World's first e-book that banks your voice launches

One of the most distressing elements for those with MND is the potential, and reality, of losing their voices. It's been a focus of many an Association campaign in the past and now an alternative voice bank solution has been developed.

"I will always be me" is a short story, written by New York Times best-seller, Jill Twiss. The story is written from the perspective of someone living with MND, explaining to their loved ones about the condition and their experience.

Not only is the story itself valuable, but once read, the recording is uploaded and transformed into a digital voice which can then be used with communication devices.

The MND Association will provide funding for people with MND living in England, Wales and Northern Ireland to take part, thanks to donations from Dell Technologies and Intel.

Visit iwillalwaysbeme.com for more information.

Treasurer's list of monies received and spent

Thank you to everyone for their contributions. The below are the cleared funds received for the fourth quarter 2021.

(All information was the best available at time of going to press).

Money received

Money from activities

Fundraising - Giving Lottery	£26
London Road Methodist Church Horsham	
Speakers Fee - Chris Sheridan	£100
Collections and Donations	£408
Donation - Mrs A Warmachowski	£100
Sussex Hat Hire - Jenny Rimmer	£2,008
Easyfundraising - Julie Unsted	£16
Branch Sale of Xmas Cards	£74

Donations and gifts

Amber Maidment	£25
Anthony Gimson	£500
Anonymous	£230
Anonymous	£20
Ted Dente - in lieu of Xmas Cards	£30
On behalf of Derek Dente	
June Hewins, Ann Wyatt & Jo Crompton	£100

Money spent

Financial support for members and carers

Riser Recliner Chair	£615
Washer/Drier	£1,500
Hands Free Drinking Systems (Five units)	£420
Members & Carers Xmas Vouchers	£450

Financial support through National Office

Chief Executive Appeal:

Voice Banking	£2,000
Research	£2,000

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Association Visitors:

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Keep in touch...



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If you do not wish to receive further information please contact a member of the Committee.

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