West Sussex North
December 2024

Welcome to our December 2024 Branch Newsletter

Since we last published a newsletter, in April, it has been a busy time for the West Sussex North branch. As we approach year end, we want to take the opportunity to update you on a host of news items, including activities to support people living with MND, some impressive fundraising stories, and a couple of departures from our committee.

We start with a new-look front page, including a photo from our region, taken by a regular supporter of our branch, Sandra Blaskett. This beautiful autumnal scene was captured at Warnham Millpond, in Horsham.

Also in this issue:

Farewell to Committee Members Julie and Joan....

September's branch social, at the Haywards Heath Centenary Hall, was a chance for members to get together over tea, coffee, cakes and conversation.

It was also the chance to bid farewell to branch Chair Julie Taghan and long-time committee member Joan Moon, both of whom have decided to step down, though both have promised to keep in touch.

Whilst we were extremely sad to see Julie and Joan go, we were happy to be able to express our gratitude for everything they have done for the branch, over many years. *Thank you!*

....presents an opportunity to get involved

With the departures of Julie and Joan, we are looking for new committee members and volunteers. These are wonderful opportunities to get involved in a variety of ways, contributing to the vital work of raising awareness, fundraising, and supporting local people living with MND, or affected by MND.

In particular, we are seeking a dynamic branch Chair, with excellent interpersonal skills and strong leadership qualities, to work with the existing committee members, to help us continue to achieve our goals.

If you are interested in getting involved, or know someone else who would like to join us, please contact lisa.burnard@mndassociation.org.

Another successful Horsham collection

Our 2024 Horsham collection took place on Saturday 22 June, the day after Global MND Awareness Day. This has always been a successful and important fundraiser for us, and this year was no exception. With great support from Horsham's shoppers, we were delighted to raise a total of £1,560.

As has been the case for many years, this year's collection was organised by Sandra Spriggs. Sandra has since decided to step aside, allowing others to step in to organise future collections.

The work and commitment required to organise this annual collection are significant, so we want to take this opportunity to thank Sandra for having contributed so much to the branch, to support people in our area who are living with MND.

PS: Our next Horsham collection day is provisionally scheduled for 21 June, 2025 – date to be confirmed.

Chat With Lisa Burnard, Area Support Coordinator, Motor Neurone Disease Association

Lisa, can you start by explaining your role as Area Support Coordinator?

Of course! I cover all three Sussex branches, which currently support 163 people with MND. A key focus is on building strong relationships with local service providers, such as care centres/ networks, care coordinators, multi-disciplinary health and social care professionals, hospices, and other non-statutory partners. I'm also responsible for recruiting and managing volunteers.

Ultimately, my goal is to ensure that people living with and affected by MND receive exceptional service, through improved local support and a greater awareness of MND in the community. This in turn enables people living with MND to make informed choices, tailored around their individual care and support needs.

Can you describe the path that brought you to your current role?

I started my career in social care, providing short-term rehabilitation to adults being discharged from hospital back to their homes. The aim was to ensure that each person had time to recover and complete their rehabilitation goals, in order to prevent repeat hospital admissions. This role developed my passion for personalised support.

I then worked for five years in a community mental health team, supporting people with enduring mental ill health. This later led to me working with a homeless charity in two large London hostels, supporting homeless people who also suffered from chronic ill health. I spent 10 years working with a fantastic group of people, who taught me the meaning of empathy and equality.

Having taken a career break to care for two family members who were very unwell, I resumed my career in March 2020 – just before lockdown – with the MND Association.

I initially worked In the West London and Surrey area, but in May 2023 I moved to Sussex, and was fortunate that the MNDA let me transfer my role to Sussex at the same time.

What motivated you to join the MND Association?

Having previously worked with chronically ill people and carers, I felt the MNDA role would be a great opportunity to focus on one diagnosis, to learn and understand the impact on the person suffering from MND, and on their family. Given my experience, I was confident that I could help the MNDA provide excellent local support and build strong professional relationships with the NHS and non-statutory services. This would help to meet the needs of people living with MND.

What does a typical day or week look like in your role?

I could be liaising with a local health professional, who needs advice on the different grants the MNDA offers members. Or attending Multi-Disciplinary Team meetings, offering guidance to the families of people who have recently been diagnosed with MND.

When new members from Sussex join the MNDA, I contact them to ensure they have all the support and information they need.

I also co-facilitate the South-East Recently Diagnosed Online Group, with a person with MND. On a monthly basis, this is a chance to support people just starting out navigating the complex health and social care system.

Last, I work with our volunteers. I help existing volunteers, with advice or answers to queries; I help to recruit new volunteers; and, with colleagues, I present online training to these new volunteers.

Lisa Burnard

What are the greatest rewards of the job – and the greatest challenges?

I do feel a sense of professional pride in the positive relationship the volunteers and I have built with NHS colleagues, as this is a real asset in meeting peoples' support needs in a timely fashion. It also enhances the collaboration between these professionals, the charity and our members. I'm also immensely proud of the MNDA's achievements in raising awareness of MND, championing the cause of unpaid carers and campaigning for better services and access to medical trials

Another reward of the job is seeing first-hand the fundraising efforts of our volunteers, which are truly humbling..

However, we continue to face challenges, such as recruiting committed volunteers, in order to offer more support to people with MND. Recruitment is made harder by the cost-of-living crisis, as potential volunteers drop out due to increased work hours, or family commitments.

There is always room for improvement, and new goals to achieve.

Finally, what impact do you believe the MND Association can make on the lives of people living with MND?

I personally feel that the impact of the MND Association on the lives of people with MND, and of those affected by MND, is immeasurable.

Awareness of MND has never been at such high levels, due to the amazing fundraising efforts at both a local and national level. At the practical level, the MNDA offers a range of services, such as timely personal support and guidance from our volunteers, or specialist literature and counselling for children and young people affected by MND.

And most importantly we continue to campaign and help fund research into a cure for MND.

Are you caring for a person living with MND? Why not join our online carers' meeting?

A reminder that we hold online meetings, every two months, to enable carers to connect with each other, to discuss various subjects and issues, and share experiences. We are here to answer your questions, lend support and facilitate discussion.

If you would like to join, we would love to welcome you to the next West Sussex North Carers Meeting, on **Thursday 16 January, 2025, at 7.30pm.**

Zoom link here.
Meeting ID: 862 5164 4904
Passcode: 006036

Branch Fundraising Update*

- **Easyfundraising: £462.81**
- **Recycle for Good Causes: £40**
- **Giving Lottery: £620.40**
- **Just Giving: £680**
- **Text2Donate: £25**

Thanks for your support!

*** based on information available at time of publication**

National News

In the latest MND Matters podcast,18 months after announcing his diagnosis of MND, actor Michael Patrick discusses his role in a special adaptation of Shakespeare's Richard III. To listen, click here.

A Tale of Two Cycle Rides, in Support of the MNDA

Jonathan Holland, Land's End to John O'Groats – in his own words

"In May, I cycled from Land's End to John O'Groats, in aid of the MND Association, raising almost £3.5k for the West Sussex North branch and for the national research programme. My inspiration and motivation for the ride was the amazing fundraising of Kevin Sinfield CBE and of course the late rugby greats, Rob Burrow CBE and Doddie Weir OBE.

The ride of over 1,000 miles, with total climbing of 55,000 feet, was the most gruelling thing I have every done. Every day required a laser focus, constantly packing and unpacking, eating and drinking, tending body and bike, oh and riding too! Averaging eight hours in the saddle every day for two weeks. Always unsure which part of me would hurt the most and what each day would bring, whether I would be soaked, frozen, windswept, overheated or sunburnt – I was all those things at some point!

As well as being a huge physical and mental challenge, it was also enjoyable and exciting; a hugely rewarding experience, with a great sense of achievement and camaraderie. By using an experienced tour company that curated the route and took care of the daily logistics, I was able to focus on the cycling.

It was very poignant to complete this challenge just before Rob Burrow passed away. His dignity inspired me, and so many people.

Would I do it again? Let's just say I have been looking at a couple of new cycling challenges in Italy and Portugal in 2026, and would plan to ride in aid of the MND Association once again!"

Charlie Sheppard, RideLondon for MNDA

On Sunday, 26 May, Charlie Sheppard took part in the annual RideLondon cycle ride, a closed road event which allows the public to enjoy cycling through London. If you saw any TV footage, you would have seen families with young children on their bicycles, a penny farthing rider, recumbent cyclists and lots of MAMILs!

Charlie had signed up to cycle the 60-mile route, which started at Embankment and took him out into the Essex countryside, through Epping Forest, and then to the finish line at Tower Bridge. The ride started cloudy, and eventually the heavens opened; unfortunately, Charlie was soaked through for the last 15 miles of the ride (schoolboy error to not stop and get a waterproof jacket on).

Despite the rain, he took 3.5 hours to complete the ride (including a small snack break) and arrived home tired, hungry but delighted with his efforts. Many thanks to all those who sponsored him. He raised a grand total of £680, plus Gift Aid, for MND Association Head Office.

Murder at the School Reunion

After a successful Murder Mystery event in 2016 (yes it was that long ago), we invited the wonderful Goring Regional Occasional Players to join us for another "dramatic" evening.

On 27 April, 80 guests filled the hall at Greenway School, Horsham, for this unique reunion, and were entertained by GROP with their usual tongue-in-cheek brand of humour (plot characters included Mr 'Rigger' Mortiss, Mike Stand and Grace Quirell) and plot building. The story followed a Reunion of the Class of '74 from St Cleve Comprehensive, where old school friends were introduced one-by-one to the audience, before the main event of the Reunion, a concert by the St Cleve City Rockers, took place on the school roof. You could quickly see the error of having a concert on a school roof (no Health and Safety rules apparently) and, of course, someone fell – or were they pushed?!

The Q&A with the audience was a fun way to determine *whodunnit*, and the final reveal had everyone laughing, as each character stepped forward to reveal the truth.

The audience and players all enjoyed a tasty fish and chip supper during the interval, and a very successful raffle and auction (thank you Ian for your paintings) meant that the evening raised £1,087 for branch funds.

Our thanks go to the Players for their support and all those who gave raffle and auction prizes.

Walk in Memory of a Dear Grandpa

When Hannah Hirst's grandpa, Robert, was diagnosed with MND, she decided to do something to raise money for research into this devastating disease.

Sadly, Robert passed away earlier this year, but Hannah and her good friend Lara Worth, both 12 years old, were determined that the walk would go ahead. They planned to walk the 95-mile High Weald Landscape Trail, from Horsham to Rye.

It was decided to complete the walk in nine stages, at weekends during July and August. The girls were accompanied by family and friends on each stage and to date have raised an astonishing £5,497.

What an achievement, Grandpa would have been so proud of you.

A Wonderful Afternoon of Music at the Shelley Arms

Back in July, on a beautifully sunny Sunday, a large crowd gathered in the beer garden of the Shelley Arms in Broadbridge Heath, for an afternoon of wonderful live music. Entertaining the crowd were Bad Girls Groove, who according to their website are “3 funky female singers … putting an original twist on funk, R&B and blues songs”. This description proved to be spot on, while their infectious energy, as they performed a succession of crowd favourites, had people of all ages singing and dancing along!

On guitar was branch member Roger Bolt, whose wife Julie is living with MND. With friends and family in the crowd, there was a great atmosphere and fantastic support for the MND Association.

The staff of the Shelley Arms kept us all fed with a lovely BBQ, and generously gave part of the proceeds to our branch. With donations from the audience, a total of over £500 was raised in support of MNDA West Sussex North.

Our thanks go to Bad Girls Groove, the Shelley Arms, and everyone who supported our branch on the day.

A Date for Your Diaries – Horsham Quiz Night on 13 March 2025

Early notice of an event taking place in early 2025. The Red Deer pub, on the Carfax in Horsham, will host a quiz evening on Thursday 13 March, in support of our branch.

The Red Deer regularly hosts quiz nights, to support local charities – or in our case, local branches of national charities. Taking part on 13 March will be the pub’s regular quizzers, together with members and supporters of MNDA West Sussex North branch. The winning team will receive a prize donated by the Red Deer. There will also be a raffle, the proceeds of which, along with a small entry fee paid by all attendees, will go to our branch.

Details will follow closer to the time, but for now, please mark the date in your calendar.

Your West Sussex North Branch Committee

Vice Chair: Chris Sheridan

Treasurer: Keith Walder

Association Visitors:
Chris Sheridan
Mike Agius

Secretary: Christian Goldsmith

Committee Member/Fundraising:
Sue Sheppard

Keep in touch…

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

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