



Walk for MND - Brighton Seafront Saturday 13th August, 2pm

If you haven't already - save the date!

After last year's successful Brighton Seafront fundraising walk, in collaboration with the other MND Association Sussex branches (West Sussex North, West Sussex South and East Sussex), we are doing it again this year.

In total, between the three Sussex branches, over £4,000 was raised and it would be great to achieve the same this year.

The walk is a 4-mile round trip between the Big Beach Café, Hove Lagoon to the i360/West Pier Brighton and back again.

We'd love you to join us for our second inter-branch walk along the Brighton Seafront - a simple walk wearing MND T-shirts or something blue and/or orange.

Some of us will have collection buckets to raise what we can along the way. The Seafront is flat and therefore easily accessible for wheelchairs, children, dogs etc. so

please come along for either a 4-mileround trip or 2 miles one way.

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

To donate please visit: <https://www.justgiving.com/fundraising/mnda-wss>

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Interview with Professor Majid Hafezparast

Professor of Molecular Neuroscience, School of Life Sciences at University of Sussex

What drew you to researching molecular neuroscience?

The brain, being the most complex organ in our body, has always fascinated me and understanding how the molecular events in the brain and the rest of the nervous system lead to behaviour drew me to molecular neuroscience.

Can you explain what you are researching at the moment?

There are three main lines of research that I am currently pursuing. One area is seeking to answer the longstanding question of whether age-related reduction in the function of cytoplasmic dynein, a molecular motor responsible for the transport in neurons, predisposes neurons to degrade and ultimately lead to neuronal cell death in neurodegenerative disease. We are looking further to see whether when combined with minor mutations in MND-related genes, it can lead to development of MND.

Another focus of my research is to identify changes in a group of molecules known as non-coding RNA (ncRNA) and find patterns of these changes in the blood of people with MND as potential biomarkers of MND. Biomarkers are increasingly regarded as important components for successful development and trialling of new treatments for any neurodegenerative disease. Additionally, they could provide much needed certainty to people with MND and their families by helping to reduce the delay in providing a diagnosis through a simple blood test.

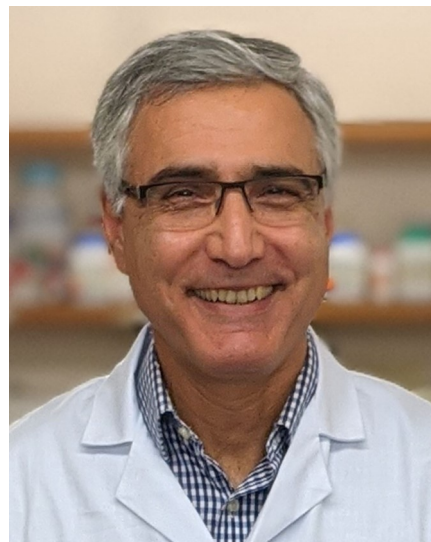
The third area of my research focuses on the role of ncRNA that are released from the microglia in the pathogenesis of MND. Microglia are the immune cells of the nervous system that play a crucial role in the maintenance of connections between neurons and in protecting the central nervous system. We have evidence that microglia release, in addition to cytokines, ncRNAs can potentially affect gene expression in neurons and consequently cause them to become dysfunctional.

What do you see in the near future for MND with regard to diagnosis and treatments?

Typically, MND has complex multifactorial causes and it requires a multiprong approach for diagnosing and treatment. For that reason, I think the current emphasis on identifying biomarkers of MND as well as the developments in genome analysis and machine learning, will help in the creation of more targeted therapeutic strategies.

What do you enjoy most about your role?

In my role as a scientist I enjoy the challenges of finding the answers to important questions that could help our understanding of the nervous system in health and disease. As an educator, it's sharing my knowledge and experience with the younger generation. I also take great pleasure in communicating my research with the general public.



What's been the single biggest factor enabling the advancements in MND research in recent years?

I believe that the sequencing of the human genome has had tremendous impact in speeding up the discovery of new genes that are associated with MND. These discoveries in turn will not only help us to better understand the affected cellular pathways in MND, but also to highlight potential therapies to treat people with MND.

Can you tell us something surprising about yourself?

Have you heard of the phrase 'this might come in handy one day'? That's me! I keep stuff in case they come in handy. And I'm good at fixing things. For example, just last weekend I fixed a garden chair using some scrap metal from an old greenhouse, which I had kept for nearly 18 years.



Join us for a Golf Challenge in Horsham this July!

Horsham resident, Ian Walder was diagnosed with MND recently. He is keen to do all he can to support the Association in it's work. He is organising a 'golf marathon' at Rookwood Golf Club in Horsham, running from Monday 4th July until Saturday 9th July.

Ian says: *"I wanted to do something while I can still walk, or at least waddle, so I thought I would bring together my love of endurance events and golf. The golf marathon - 4 rounds of 18 holes, being close to 26 miles. We aim to raise as much money as possible*

for the West Sussex North branch of the MND Association. There are 5 tee times available per day (up to 20 golfers), so if you want to join me and my golf society friends on one or more days, I would be pleased to hear from you."

There is a £5 registration fee, which will be donated to the branch, plus a £23 cost per round of golf.

To take part get in touch with Ian now on ian@vincentpress.co.uk or call on 07919 067441.

St George's Park Spring Fayre raises over £2k

Resident of St George's Park retirement village, near Ditchling, Ann Kember, regularly organises fundraising events for charity, and on 9th April held a Spring Fayre in aid of our Branch that raised a magnificent £2,235.

Because of a recent Covid outbreak in the village it had been decided not to have the usual outside traders visit in person, but a couple of them took advance orders for chocolate and celebration cakes and one man sold hand-turned wooden pen sets that were very popular.

Liz Carter and Joan Moon from our Branch attended and helped at the bric-a-brac stall which had a colourful display of items from good china to greetings cards, most of which they sold. Our Branch also provided prizes for the tombola.

St George's Park has a lively community with many clubs, including a talented group of ladies in the Craft Group who made lots of popular items including festive bunting, and the Art Group displayed their paintings. Another lady helps disadvantaged young people in Rwanda and brought along a number of beautifully made travel bags that went very quickly.

There were homemade bread and cakes that soon sold out, books, hand made cards etc, so it was truly a community effort. At the end there was a rather raucous auction of some of the left-over goodies that was great fun.

Sadly we have no photos to show you as the man who took them damaged his phone (echoes of The Thursday Murder Club By Richard Osman that was based on St George's Park!), but it was a lovely day enjoyed by all.

Final fundraising hoorah for hat hire agency

As many of you will know, long-time supporter, Jenny Rimmer, has finally hung up her hats and Sussex Hat Hire has closed. Jenny has been running her hat agency for the past 15 years, with all profits coming to the Branch.

Although unable to find someone to take over the agency as a going concern, as a result of the article about Jenny and her support of MND in *Lindfield Life*, she managed to sell 150 hats which raised a further £3,300 for us.

The remaining stock were donated to St Catherine's Hospice who



will be selling them through their bridal store in Horsham.

Thank you Jenny for your unwavering support of the Branch. We know that you will miss helping people find the perfect hat for those special occasions, but we also know you're thrilled to get your spare room back!

Fundraising update

With all of the different fundraising platforms and options to now be able to donate to the Branch - whether that be through your usual online shopping, recycling or straight forward donations - we wanted to keep you updated and say thank you!

Easyfundraising: £245.68

Recycle for Good Causes: £40

Giving Lottery: £408.40

Just Giving: £380

Text2Donate: £25.00

Easyfundraising just got even easier!

easyfundraising
feel good shopping | £41M Raised

The Donation Reminder is now available on mobile!



Great news, you can now get the #easyfundraising Donation Reminder on your iPhone and iPad!

Simply download their app and enable the Donation Reminder feature on your Safari browser. They'll then pop up every time a donation is available.

This means our branch won't miss out on any donations as you're shopping online using your mobile! Visit www.easyFundraising.org.uk/mndawestsussexnorth to start today.

Branch Socials

Put the dates in the diary now for the in-person Branch socials taking place at The Ark Community Centre, Turners Hill, 3pm - 5pm:

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

Short Mat Bowls Competition raises funds for our branch

As mentioned in our previous newsletter, our Branch is lucky enough to be one of the chosen charities of the West Sussex County Short Mat Bowls Association.

The fundraising event for this was held in March and we are very grateful to have received a cheque for £300. Thank you to the Association, and to Chris Sheridan for collecting it for us (photographed opposite).



Treasurer's list of monies received and spent

Thank you to everyone for their contributions. The below are the cleared funds received for the first quarter 2022.

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

Money received

Money from activities

Fundraising - Giving Lottery	£26
Brighton Road Methodist Church, Horsham - Ladies Wednesday Club	
Speakers Fee - Chris Sheridan	£32
Sale of Homemade Xmas Decorations - Gew Cross	£40
Recycling for Good Causes	£41
Branch Sale of Xmas Cards	£256
Lyndsay Webber Fundraising: Bishops Cleeve Methodist Women's Fellowship Coffee Morning	£620
Jennie Swann - Surrey Three Peaks Challenge	£1,045

Donations and gifts

JustGiving - Anonymous	£100
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Donations and gifts in memoriam

In mem. Clive Keen	£370
Margaret Peet - in mem. Jean Binner	£15

Donations and gifts in memoriam continued

Brighton Road Baptist Church Horsham - Womens Evening Fellowship	
In mem. Audrey Smallwood	£82

Money spent

Financial support for members and carers

Riser Recliner Chairs (two chairs)	£780
Course of Massage	£270
Physiotherapy	£250
Headcollars for Princess Royal Hospital (x3)	£634

Expenses

Hire of Ark Meeting Room 2022 (net of credits for meetings missed)	£228
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Annual Transfer to National Office

To Care	£3,631
To Research	£3,631

Your West Sussex North Branch Committee

Chair: Julie Taghan

Vice Chair: Chris Sheridan

Secretary: Liz Carter

Treasurer: Mike Abbott

Newsletter Editor: Joanne Rogers

Committee Member: Joan Moon

Association Visitors:

Chris Sheridan
Buzzy Quested
Mike Agius

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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