

Newsletter

Thank you and farewell to Dr Steve Dyer who retires from position of Branch President



(photo of the adoption of the MND Charter by West Sussex County Council)

Written by Dr Steve Dyer

It was while working at Princess Royal Hospital that my path first crossed that of the then Branch Chair, Carol Rieley.

Little did I realise that my corridor chats would lead to being invited to be Branch

President - an honour which I was happy to accept. That was in 2011.

The role, I understood, was to harness my experience both in Palliative Care and in the local medical community enabling it to benefit the Branch and its members.

Despite not being expected to attend the committee meetings, I felt it vital to know

concerns as they arose. Once Carol left the Chair, I sought to give steering until we found our present Chair, Julie.

Although less available recently, I have very much enjoyed supporting The Ark Teas, coming alongside many wonderful people living with MND as well as their Carers.

Last year I was pleased to lend weight to our ultimately successful push to get the MND Charter adopted by West Sussex County Council. I hope this will enable its services to give our members the help they need and so deserve both now and in the future.

It has been a privilege and pleasure to be associated with the Branch in this way for the last eight years but I feel it is time to vacate the position and open possibilities for the Branch to move onwards and upwards!

My sincere thanks go to our excellent hardworking committee and volunteers who continue to make West Sussex North such a great Branch and to all of you for making the tenure such a positive experience.



GivingLottery
Powered by TheGivingMachine

Raise money & have a chance to win!

Want to raise money for the Branch? And 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.

And you have the chance to win a £25,000 prize if you match all 6 numbers in the correct order. What are you waiting for? Have a go!

Carers walk in memory of Ron Stevenson and raise over £700

By Tracey-Jayne Henn

In 2016, a supervisor at the care company I worked part time for called to tell me that I was to do a call for a man with MND, and with his life limiting disabilities needed assistance for almost every part of his life. And so I met Ron.

Despite his immobility Ron was an active man. He took on the world. Campaigning for common good.

But most of all he was funny. Compassionate. And inspirational. He cared deeply for his carers. Every morning he would greet and ask us how we were. Some calls were filled with so much laughter, his beloved Gill would have to shush us down, else nobody was getting into bed or going home. We all became family. And everyone of us has a special story we could share. Rubbing his sore foot for ages before realising he had fallen asleep. Sitting on the floor as he rambled on making no sense when delirious with fever. The wicked man sometimes played dead, scaring more than one carer.

Ron never complained. His acceptance inspired us all. His kindness was humbling.

On Sunday August 18 Grace and I put him to bed after a happy day celebrating his birthday. He was in fine form, there was much merriment that call and yes we got shushed again. Later that evening Ron called Grace down, and after some difficulty breathing, passed away peacefully.

In the aftermath of his passing, we, his carers met Kerry, who worked at the hospice. Having only met Ron in April this year, they were already firm friends.

Kerry had been part of the team that took Ron and a few others from the Hospice up to Devils Dyke. After-

wards they all had a drink, on Ron. Ron loved his time up there, telling us he had felt more free than he had in ages. He couldn't wait to share the photos with us.

So when Kerry suggested a walk for Ron, to raise funds of the MND West Sussex North, we all jumped in. We all loved Ron and this was the best way we could honour him.

The rest is history. The Go Fund Me Page was set up and we shared the life out of it. On the 19th of October we walked because Ron couldn't. We were so excited to break target and afterwards met Gill for drinks in the same pub Ron had bought his last round.

We were: Emma and her daughter Imogen. Emma had been with Ron the longest as a night sit carer. Terri, Grace and I were night sit and day carers. Kerry from Hospice and her dog Jazzy.

Next year we aim to go BIGGER. Watch this space. Ron's voice will never be silenced.

"No one is actually dead until the ripples they cause in the world die away"

- Terry Pratchett, *Reaper Man*



**Save the date:
AGM 2020**

Sunday 5th April
3 - 5.30pm
Centenary Hall, St Wilfred's
Way, Haywards Heath.

Recycling for Good Causes

Thank you to everyone who has supported us already, and remember to mention to friends and family over the Christmas when they are having a clear out!

Recycling for Good Causes use a network of experts to resell your donated items with the proceeds going to our Branch.

You can recycle anything from old cameras, ink cartridges, jewellery, currency and stamps, game consoles, laptops, mobile phones and tablets.

Good for them and good for us! For more information about how it works, visit: www.recyclingforgoodcauses.org.

Branch chosen as charity of the year by Veterans' Section of Copthorne Golf Club



The West Sussex North Branch is delighted to have been selected as Charity of the Year by the Veterans' Section of Copthorne Golf Club for 2019/20.

Various golfing and social events will be organised from October 2019 to September 2020 to raise funds.

Branch Campaigns Contact, David Setters, who lives with MND, tells us that this marvellous opportunity has arisen serendipitously through local contacts and his brother.

"The new Veterans' Captain, Sean Hayes, lives in my village where we both frequent the local pub. It turns out that he also knows my brother, Les, who also plays at Copthorne. Many people in our village have been very supportive of myself and Helen and it is very kind of Sean to adopt our branch as charity partner for the year."

After the success of previously being the charity of the year for Haywards Heath Golf Club, we cannot wait to keep you posted on the events and fundraising efforts at Copthorne.



M Professional Football Academy donate £500

Filipe Morais, the owner of M Professional Football Academy, understands the impact MND has on those close to him. Former team mate and good friend, Stephen Darby, is living with MND.

Filipe, who now plays at Crawley Town FC, arranged for a donation of £500 to our Branch to aid our work supporting people locally with the disease.

To find out more, there is also the Darby Rimmer MND Foundation, which aims to create awareness of MND, to fund and assist research into the illness. darbyrimmermnd.co.uk/



Spectacular £1,700 raised at annual quiz night

This year's quiz night smashed all previous totals raising a whopping £1,700 for the branch.

The quiz, held at Haywards Heath Golf Club on 8th November saw 18 teams battled through fiendishly difficult questions set by our new quiz master Mitch.

This year saw the first auction running alongside the ever-popular raffle. Our auction lots included a night for two at

the brand new Hard Rock Hotel in London and Tea for Two at The Savoy. Over 15 raffle prizes were also provided by companies including Tuffnells, Ockenden Manor, Bolney Wine Estate and Rushfields Garden Centre

We are extremely grateful for the ongoing support of our quiz night and for the generous companies who provide such extraordinary prizes.

Roll on next year!

Branch Socials 2020

Next year's Branch socials will be held at The Ark, in Turners Hills, between 3-5pm on the following dates:

- Sunday 23 February
- Sunday 14 June
- Sunday 16 August
- Sunday 11 October
- Sunday 6 December

Committee

President

Dr Steve Dyer

Chair

Julie Taghan
07709 425957

Julie@
mndwestsussexnorth
.com

Vice Chair

Chris Sheridan
01444 245486

Secretary

Liz Carter
01444 483952

Treasurer

Mike Abbott
01444 455084

Newsletter

Editor

Joanne Rogers

Committee Members

Christine Colbourne
Joan Moon

Association Visitors

Chris Sheridan
Veronica Mamoany

Other ways of getting in touch...

www.mndwestsussex
north.com

westsussexnorth
@mndassociation.org

Facebook:
mndwestsussexnorth

Twitter:
@mndwestsussexnorth

Treasurer's List of Monies Received & Spent

Thank you to everyone for their contributions. The below are the cleared funds received for the third quarter 2019.

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

MONEY RECEIVED

Money from activities:

AGM - sale of teas and cakes	£11
Fundraising - Giving Lottery	£45
Barbara Dente - WWII Vehicle Show	£122
M Professional Football Academy (Crawley Town FC)	£500

Donations and Gifts:

Pat & Colin Bendall	£200
P & Mrs P Gardiner	£27

Donations and Gifts in memoriam:

Marilyn Emmett (in mem. Brian Emmett)	£10
David Julian (in mem. Jean Julian)	£600
In memoriam Ron Stevenson	£1,873

Other income:

Bank Interest	£127
---------------	------

MONEY SPENT

Financial Support for members & carers:

St Peter & St James - Support Staff costs	£110
Quality of Life Grant (two grants)	£1,000
Stairlift	£1,250
Riser Recliner Chairs (two)	£1,000
Nebuliser (two)	£92
Pulse Oximeter	£473
Miscellaneous Equipment	£12

Expenses:

Visitors - Travel Allowance	£156
Hire of Ark Meeting Room 2020	£458

PUBLISHED BY: West Sussex North Branch of the MND Association.

The views expressed in this newsletter are not necessarily those of the MND Association. If products and services are mentioned, these should not be taken as recommendations by the Association, who cannot be held responsible should any complaint arise.

We would like to keep in contact with you about the important work we do. If you do not wish to receive further information please contact a member of the Committee.

MND Connect

The number is
0808 802 6262