motor neurone disease association

West Sussex North

September 2023

Art Exhibition and Sale Raises £1,600 for West Sussex North Branch

On Saturday 24 June, Southwater resident Ian Walder held an Exhibition of his artwork at Rookwood Golf Course, Horsham.

Ian had very kindly set up the Exhibition, along with his lovely wife Jane, with the aim of donating 20% of art sales proceeds to our branch, plus 100% of the proceeds from a raffle held on the day.

The art was on display in the Club room during the week running up to the Saturday and, following a last minute change of plans by the club, the artwork was then moved to the golf shop, which ended up being a perfect space for Ian's art.

With a wonderful turnout of over 100 people, Ian sold 27 of his 58 pieces and made a massive £1,600 for our Branch. Many thanks to Ian and Jane.

In this issue:

Former secretary Liz Carter raises £960 for the Branch, by running the Race to the King

In June, Liz took part in the Race to the King, fundraising for the Branch:

“As I made the difficult decision to step away from the role of Branch secretary, I thought it would be an opportunity to do one last fundraiser. I figured if it’s the last one, then it should be a big one. My first marathon in 2003 was via a charity place for the MNDA, and I did another for the branch in 2012, to celebrate entering my fifth decade. So what better way to recognise my sixth decade than with a 50k event?

Training was testing, as my running buddy Emma and I were both battling injuries, and two weeks before the event I tested positive for Covid. We spent many hours together, running on the South Downs with our dogs, enjoying the beautiful scenery with only a slight nagging doubt about what we’d signed up to.

But on a remarkably warm day in June, Emma and I headed to Goodwood Racecourse, to the start line of Race to the King, along the Monarch’s Way trail. The run, which started and ended on the Downs, took us along the beautiful Sussex coast around Pagham, Bosham and Chichester Harbour. We were well looked after at the aid stations by volunteers, who refilled water bottles and refuelled us with snacks.

We were aiming to complete the race in 6 hours, but at 35k Emma’s hip started hurting, so we amended our aim (we never leave each other) to finishing the race safely, and

came in at just over 6½ hours. I was 85th home out of 351, the 26th woman out of 191 and 6th out of 37 in the women over 50 category!

Overwhelmed, exhausted and happy to have raised £960 for the Branch. Too tired to take a photo, except this one!”

Partnering with Haywards Heath Arts Festival

On 9 September, we were delighted to join the Haywards Heath Arts Festival’s marquee, at the Town Day. They had lost a much loved member of their team to MND earlier this year, so chose to support the MND Association, along with Hope and Homes for Children, a Ukrainian children's charity.

On a roasting hot Sussex day, Chris Sheridan, Sue & Charlie Sheppard, Liz Carter, and Anna Maerker and her partner Simon, set up a display of literature, balloons and banners, to wave the flag for the Branch. Visitors to our stall were also asked to Guess How Many Pieces of Pasta were in the jar, to win a box of Celebrations! Donations were moderate, but we were pleased to have the chance to chat to a number of people about their experiences of living with MND.

Interview with Jeremy Vine

Patron of the MND Association

Jeremy, thanks for taking the time to answer questions for our branch newsletter. Could you please start by introducing your role as a Patron of the MND Association?

For me it's about giving a bit of support where I can. Motor Neurone Disease needs a higher profile. The people who are suffering need their voices to be heard. Above all, they need time. The most wonderful thing for me has been meeting people with the illness who have the time to take 10 minutes for a chat. I always wonder, with an illness so serious, how anyone can spare the time for me! It is profoundly uplifting.

You're a Patron both of the West London & Middlesex branch, and of the national MND Association. How do your local and national roles differ?

In my local role, I host an annual quiz at the branch in Brentford!

With the national role, I just help out wherever I can. The joy of the MND Association is that one day you're meeting Princess Anne and the next, you're asking "what colour was Noddy's hat?" for a branch quiz.

As a Patron, where do you feel you can add the greatest value?

Sometimes, it will just be a conversation. Say, I'll be talking to someone at the BBC and they'll ask what illness Stephen Hawking had, and I'll say it was MND … and then go on to explain.

Of all the charities you could have supported, why did you choose the MND Association?

I'm not sure I ever consciously made a choice. I just struck up a conversation one day in Chiswick, where I live, with a wonderful woman called Janis Parks. She was walking past my house and said hi. There had been MND in her family and she was very committed to the charity. She got me involved! We lost her a few years ago - for reasons unrelated to MND - but she was so inspiring.

From your time supporting the MND Association, do you have any particularly memorable or inspirational experiences to share with our members?

I remember very clearly a lady who was in her mid-eighties and, although seriously ill and with the weakest voice, spoke to me and my daughter, then aged eight, at a West London branch Christmas meeting. She was so charming, so lacking in self-pity. She smiled at Anna and I knew she had made a huge impression.

With so many commitments, including your promotion of cyclists' rights, how easy is it to carve out time for your role as Patron of the MND Association?

If you do what you love, you never run out of time! The cycling thing took off by accident, as I was uploading videos of my cycle commute in London; the other day I calculated that I'd hit 100 million views. But being involved with the MND Association is a greater privilege than any other.

Moving to your day jobs, of the estimated 64,000 calls (and counting) you've fielded on your Radio 2 lunchtime show, is there a particular call that's had a notable impact on you?

We recently had a call from a woman who is raising money to buy uniforms for women soldiers in Ukraine. They currently have to wear men's uniforms, even men's underwear. I was listening to this woman speaking from Kiev about raising money to buy pants and I found it unbearably moving.

A final question, for anyone who is also a fan of your brother, Tim. Is he as funny in person as in his comedy shows, or does he save the laughs for his live audiences?

Oh, Tim is funny! But when I'm with him it's a different kind of humour. It's the thing where we both laugh about stuff that happened at school or whatever. On stage he is a pun machine, totally different! I'm so full of admiration for what he's done.

Join our next carers' support group online meeting

Hosted by Beck Cedar, on Wednesday 22 November, 7.30pm

Zoom Link

Meeting ID: 841 0698 6241

Passcode: 965838

Final Branch Social of 2023

Please join us for tea, coffee, cake and conversation, plus the chance to buy MNDA Christmas cards, on **Sunday 3 December,** 3pm-5pm, at The Ark Community Centre, in Turners Hill.

Due to low attendance, this will be our last Branch social at the Ark. Please email us if you have any ideas for alternative venues or social activities.

Latest MND Matters Podcast

Don't forget to tune in to the podcast. The latest episode discusses Cultural challenges with MND. Click on the link above to listen now!

National News

Fundraising update

Easyfundraising: £313.24

Recycle for Good Causes: £40

Giving Lottery: £568.40

Just Giving: £380

Text2Donate: £25

As at 25 September 2023

THROUGH THE ROOF

People affected by MND have been disproportionately affected by the cost of living crisis. The MNDA's Through The Roof campaign is calling on the Government to urgently implement more targeted energy support, to protect people's energy bills from going through the roof.

To learn more about the campaign, including the MNDA's report on the experience of households affected by MND during the cost of living crisis, click on the following link: **Through the Roof**

Peer Support CHC Group

Anyone living with MND, who needs help navigating the process of obtaining Continuing Health Care (CHC) funding, or who is facing problems with an existing care package, is invited to join meetings of the MNDA's peer support group.

The group meets every six weeks, by Zoom, and the next group meeting is scheduled for Monday 16 October. For more information and joining details, please contact Anne Anderson:

anne.anderson@mndassociation.org

Tel: 01604 611893

Treasurer's list of monies received and spent

Thank you to everyone for their contributions. The below are the cleared funds received for the period July-August 2023.
(All information was the best available at time of going to press).

Money received

Money from activities

Fundraising - Giving Lottery	£19
Horsham Collection	£1,711
Joe Burdon - London Marathon	£10
Liz Carter - Race to the King	£230
Gift Aid	£233

Donations and gifts in memoriam

The Weald Theatre Group - In memoriam Lance Milton	£3,000

Money spent

Financial support for members and carers

Adaption Grant	£1,250
Chair Riser and Call Out Grant	£178
Riser/Recliner Chair Grant	£630

Your West Sussex North Branch Committee

Chair: Julie Taghan

Vice Chair: Chris Sheridan

Secretary: Christian Goldsmith

Treasurer: Keith Walder

Committee Members: Joan Moon & Sue Sheppard

Association Visitors:
Chris Sheridan
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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