



Golf Marathon raises over £10,000!

In the June issue we told you about the forthcoming Golf Marathon being organised by Ian Walder who had recently been diagnosed with MND. It took place between Monday 4th and Saturday 9th July at Rookwood Golf Club in Horsham. The Golf Marathon, and a number of accompanying fundraising events, in total, have raised over £10,000 – a phenomenal total!

The Golf Marathon itself was a £5 donation per golfer, and Rookwood Golf Club made a further donation of £3 for every round paid for.

Every day throughout the Marathon, raffle tickets were sold for great prizes, donated by local companies and Ian's friends. There

was also an auction including items such as 4 balls at various golf clubs in Sussex, a car valet service, an electric drill, and tickets to go to the races and see Paloma Faith or the Human League. Ian also donated 3 of his own paintings to the auction. The auction alone raised over £1,800. In total over the 4 days, including the Golf, more than £4,200 was raised.

After the Golf Marathon, a BBQ was organised at Southwater Sports Club (where Ian and his family are well known) and another raffle and auction of prizes took place. Ian donated another 2 of his paintings for auction, with local MP Jeremy Quin winning one. A total of nearly £3,000 was made at this event.

The last event was a Paint Club held in Sue Sheppard's garden (another branch member who lost her father to MND) on the Monday night which raised £305 from the 13 people who came to paint a picture of a lion and bought raffle tickets!

Also, on the Saturday £235 was raised when a friend of Ian's organised a putting competition of closest to the bottle of Moet!! Great fun for even those who don't play golf.

With Ian's JustGiving website total of £2,578, the grand total reached was £10,152.55!

In this issue:

- Interview with Rachel Thomson, Coordinator at Sussex MND Case and Research Network
- Help us find a new Treasurer
- Forthcoming fundraising events



Painting Club masterpieces

Long-standing supporter of the Branch, Sue Sheppard, held a painting club in her garden as part of the Golf Marathon series of events. Besides the funds raised for the Branch, it was a great deal of fun and we wanted to share the artistic masterpieces with you all too.

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 9th October
- Sunday 4th December



**Tri-Branch
Brighton Walk
Rearranged Date:
Sunday 28th May
2023**

Hunt for a new Branch Treasurer: Do you know anyone that could help?

After many years as a dedicated volunteer to the Branch, our Treasurer, Mike Abbott, is stepping down. So the hunt begins for a new Treasurer.

Do you know anyone that could help and would be interested?

The Treasurer is responsible for the finances of the Branch by maintaining proper records and following the Association's accounting procedures. All the Committee meetings you'd need to attend are conducted via Zoom.

The time commitment is, roughly, 2 hours per week in addition to the Committee meetings.

The person needs to have:

- Good numerical skills
- The ability to present and explain financial Information clearly
- The ability to set up and maintain financial records
- Skills to analyse simple financial information.



Full training and induction will be provided, and travel expenses will be reimbursed.

If you know anyone among your friends and family who could take on this role, [please share the website link for the vacancy](#) with them and either ask them to apply or to speak to us first if they have questions.

Thank you everyone for helping us find a new Treasurer, and thank you to Mike for supporting us for so long!

Interview with Rachel Thomson, Coordinator Sussex Motor Neurone Disease Care & Research Network



Can you tell us about the Sussex MND Care and Research Network?

The Network has several objectives to work towards as part of the grant we receive, but essentially it's about improving care and support for people with MND in Sussex, and increasing access to research.

What is your role at the Network?

It's my job to make sure we achieve the objectives! I work with the local health & social care professionals, Association staff & local Sussex branches on projects.

For example, we are working on a big project at the moment to improve psychological care for people affected by MND. I am mapping what is available and identifying gaps. Once that is complete, we will be looking at how to get funding for additional support.

I'm also part of the MND clinic with Dr Andrew Barritt at Hurstwood

Park. I try to make sure that people have as much information and make sure that they are in touch with all the right services.

I attend all the local MDT meetings, so I can liaise with the teams and this also helps to identify any service issues.

How did you get into working on MND and joining the Network?

I'm a speech & language therapist by background and was the clinical lead SALT in the Worthing neuro team. I worked with people with MND for 18 years in that role and progressive neuro conditions, (but especially MND) were always my passion. After such a long time I needed a change, so I came to help start the Network in 2016.

What do you like most about your role as coordinator?

It is really varied, I get involved in all sorts of areas such as education of professionals, service development, audits and even some research. I also really enjoy still having some contact with patients.

How can people living with MND access support from the Network?

As well as the MND clinic (which they can be referred to by their neurologist), I work really closely with all the MND Specialist Practitioners so that we can identify issues and try to improve things. If anyone has any queries, they can contact me and I'll try to help.

What are you most proud of the Network having achieved?

I'm most proud of the fact that we now have MND practitioners in all 7 of the localities in Sussex. Prior to 2019 there were none in East Sussex at all, so this has made a huge difference to care there. This was achieved by great team work from all the local teams, the Association staff and the local Branch.

I'm pleased that we have vastly improved the communication between local services and the Lane Fox Unit, which in turn has improved access to respiratory care for people in West Sussex.

How can people get involved and support the work of the Network?

Firstly, if people want to take part in research (this can sometimes include carers or health professionals, depending on the study) they can contact me.

We are shortly launching a Network Advisory Group so if people with MND or families are interested in joining see overleaf for details!

Finally, we have our annual Network Day on Tuesday 15th November, in Brighton. This free day is open to HSCPs, Association staff & volunteers and people affected by MND. It's a chance to meet people involved in MND care from a cross Sussex, local service developments, research updates and the work of the Network.

Contact Rachel on
R.Thomson@bsms.ac.uk
01273 876541

Join the MND Care & Research Network User Group!

To support and strengthen the work of the MND Care & Research Network that Rachel Thomson, Co-Ordinator, told us more about in her interview above, the Network would like to involve people affected by MND (those with the disease, carers, family members etc) more formally in service design, evaluation, and research planning.

They are looking for around 5-10 active members of the group to participate primarily online.

The main aims of the group are:

1. To advise on research projects and protocols.
2. To review written information for people affected by MND. This could be for both local information and as a resource for the review of MND Association publications.
3. To provide input and feedback on care and service development plans.

Anyone interested should contact Rachel on R.Thomson@bsms.ac.uk or 01273 876541.

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: £228.66

Recycle for Good Causes: £40

Giving Lottery: £433.60

Just Giving: £380

Text2Donate: £25.00

Donate via PayPal!

Raise funds for us, by simply using this [link to donate via PayPal](#).

Horsham Street collection

Thanks to everyone who joined us. It was so successful, we raised £1,224.54!

New Committee Member and there is still room for more!

We are delighted to announce that Sue Sheppard has joined the Committee! As many of you will know, she has been involved in the Branch since her father passed away from MND in 1988. At one stage previously she was on the Committee but has continually

been an active supporter and fundraiser throughout. We are thrilled to have her back now on the Committee!

But there is still room for more new Members. So if you are interested in joining, get in touch with Julie at Julie@mndwestsussexnorth.com

MND Matters - are you listened to the podcast?

Have you been listening to the MND Association's Podcast? All 18 episodes are available online.

They cover a range of subjects from the impact gifts in wills have made to research, personal stories, the challenges LGBTQ+ MND patients can face, an inside view on campaigning, through to the impact of an MND diagnosis on friendships.

Every podcast aims to share experiences, offer information, advise, and raise awareness of MND. Sometimes emotional, sometimes humours and always honest.

Listen here:

www.mndassociation.org/media/mnd-matters/

National News



Treasurer's list of monies received and spent

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

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

Money received

Money from activities

Fundraising - Giving Lottery	£25
St Georges Ditchling - Craft Fayre	£2,235
Jenny Rimmer - Sussex Hat Hire	£1,170
Ian Walder - Golf Challenge	£592
Lyndsay Webber Fundraising:	
Loxwood School Fundraising	£354
Jennie Swann -	
Surrey Three Peaks Challenge	£2,045
Loxwood School - Walk a Mile for	
Mrs Webber	£1,544
West Sussex County Short Mat Bowls	
Association	£300
Sale of Goods - The Ark	£27
Easyfundraising	£19

Donations and gifts

London Road Methodist Church, Horsham	£129
Shirley Crowther - in lieu of Birthday Gifts	£260

Donations and gifts in memoriam

M. A. Blake-Dyke - Sue Charman	
Tribute Fund	£30

Other income

Gift Aid - Fundraising and Donations	£1,136
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Notes

The Jennie Swann - Surrey Three Peaks Challenge has now raised a total of £3,090.

The main funds from the Ian Walder Golf Marathon will be received by the Branch in the third quarter.

Money spent

Financial support for members and carers

Riser Recliner Chairs (two chairs)	£515
Young Persons Grant	£300

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 &
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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