

Newsletter

Outstanding amount raised by Haywards Heath Golf Club



Chris Sheridan who received the cheque told HHGC members how they intend to spend the money.

With 10% going to MND's national research and clinical trials - at the Captain's request. The remainder is to be used to help local people living with MND.

Chris said 'We hope to provide complementary therapies to people with MND and their carers in their own homes.

Also at present, there is still no local community respiratory service in Sussex, patients with MND are having to travel to London for assessment and monitoring. We are therefore, out of the money raised, going to provide equipment so that the MND specialist nurse can assess the person in their home, send the results to London and then an appointment will be arranged only if necessary.

In addition travelling to London can be quite arduous for people with MND, we are hoping some of money raised by HHGC members will create a fund in place to provide/hire suitable transport to enable sufferers to travel in comfort, and reduce the stress on carers'.

Chris finished by saying 'The Charity is overwhelmed by the generosity of HHGC members and the community spirit in providing much needed funds, which will make a huge difference to local people living with MND'.

A year ago, on New Year's Day 2018, to the theme music of James Bond, the then Captain of Haywards Heath Golf Club (HHGC), Mitch Clark, and the 2018 Ladies' Captain, Margaret May (dressed as Pussy Galore), arrived in a vintage Aston Martin, for their 'Drive In'.

They were accompanied by Junior Captain Tom Hopson dressed as Audric Goldfinger and Seniors' Captain Terry Holman dressed as Q. It was to be the start of their 2018 Captaincy and fundraising year for our Branch.

Thanks to the generosity of the members of Haywards Heath Golf Club, the Branch has had a happy start to 2019. A cheque for £28,425 was presented to Chris Sheridan, Vice Chair, of the West

Sussex North Branch of MND on New Year's Day, 2019; following the clubs' year long fundraising efforts. Raffles, auctions, a darts marathon, a fashion show, a bridge drive and coffee mornings are all the usual fundraising events at the golf club.

But new initiatives organised by Mitch and Margaret included a pier-to-pier walk from Worthing to Brighton, 14 golf club members and Liam Dwyer (MND member) completed it in a wheel chair. Al and Ben Turner completed the London to Brighton bike race. Emma Pryor completed the Great South Run. The Captain's Charity Day raised amazingly over £15,000.

Sad news of the passing of Carol Rieley

June 44 – September 18

It is with much sadness, that we report our amazing previous Branch Chair of 12 years, passed away peacefully at St Peter and St James' Hospice on 22nd September 2018.

Born in Oxford in 1944, Carol grew up in New Eltham in London. Despite her school and parents' ambitions for her to be a secretary, she was determined to be a Speech Therapist. Having qualified, she moved to Bristol where she met John in 1965, they married in 1967 and moved to Lindfield in 1974 with their children Christopher and Elizabeth. Carol worked at Cuckfield Hospital, moving to the Princess Royal Hospital and retiring in 2006. She was proud to work for the NHS and felt fortunate to have had a fulfilling career having helped so many people with their communication needs.

Through her work patients with Motor Neurone Disease she knew the vital support that the MND Association could give, so when informed that the local branch was going to close she refused to let it happen. She valiantly took on the role of Chair and recruited many friends and neighbours as committee members.

In 2014, after twelve years at the helm, Carol stepped down and trained to be an Association Visitor offering support to individuals living with MND and their families. In addition to her work with MNDA, Carol continued to use her skills as a Speech and Language Therapist running a regular conversation group for the local branch of Parkinson's UK

When Carol was diagnosed with ovarian cancer in 2016 she didn't become a victim, she treated her diagnosis in the same way she approached life – with strength, with dignity and with an opportunity to meet and chat to new people. She made friends with the staff at the Sussex Cancer Centre, bringing home-made scones and John's sweet peas for the team and gave an extraordinary address to clinicians and patients at the 'Target Ovarian Cancer' conference in Brighton in 2017.

Carol and John were married for 51 years. Following her diagnosis she was determined to celebrate their Golden Wedding Anniversary which she did in style with the family at Sandbanks in January 2017.

She was feisty, loving, inspirational, charming, funny and never ran out of things to say. She read voraciously, loved the theatre, flower arranging, travelling, eating, cooking, entertaining, living.

Communication was everything to Carol and to finish on a quote that was dear to her from George Eliot:

'Voices – I think they must go deeper into us than other



things. I have often fancied heaven might be made of voices'

Carol's passing is a huge loss to the Branch but she also gave it so much and saved it from closing. We owe her a great deal.

Rest in peace.

Happy 40th Birthday MND Association

The Association was established in 1979 by a group of families affected by the disease. With little information, co-ordinated care or support available they felt 'isolated' and utterly 'helpless'. They were 'in the dark' and aimed to fill the void of care and support and encourage research into the disease.

40 years on the Association funds has done what it can to stop that being the

case, with around £15.5 million invested in a global research effort to discover causes, potential new treatments and ultimately a cure.

2019's anniversary will be marked by the Association's relentless commitment to people living with MND, underpinned by a fresh optimism that together we will deliver our vision of a world free from MND.

£1,875 raised at Crawley Down Quiz Night

On Saturday 24th November, the Bines family held their first ever local Quiz Night.

Many friends and family travelled from afar to join in with all the fun.

It was kicked off with a fun ice breaker of Heads & Tails where the winner won £50 whilst raising an additional £50 donation.

There were a range of topics covered including a London Underground Anagram Round and a Guess the Brand Logo round. Many of the raffle prizes were donated from local business and lots of people went home with something. The night was a great success with a grand total of £1875 being raised for our Branch.



Horsham Street Collection 15th June



Recycling for Good Causes

We have teamed up with Recycling for Good Causes to create a convenient and easy way for you to support the Branch, as well as the environment while having a bit of a clear out too!

Recycling for Good Causes offers a hassle and cost-free solution, whereby they use a network of experts to resell your donated items with the proceeds going to a charity, in this case the MND Association West Sussex North Branch.

You can recycle anything from old cameras and equipment, ink cartridges, mobile phones, jewellery, UK and foreign

currency and stamps, game consoles, laptops, mobile phones and tablets.

So bring along anything you can donate from the above list to the next Social, and don't forget to ask friends and family if they have anything too. We'll be keeping a running total of funds and letting you know here.

Thank you for your support and your items.

For more information about how it works, visit: www.recyclingforgoodcauses.org.

MND Register

By creating a national database about every person with MND in the UK, the aim is to improve the planning of care for people living with MND and tell researchers more about what might be causing it. To take part visit:

www.mndassociation.org/research/mnd-register-for-england-wales-and-northern-ireland/

Branch Socials 2019

Branch Socials 3 - 5pm at The Ark in Turners Hill.

- Sunday 24th February

There will be a special bring & buy at the February social, so don't forget to bring along any unwanted Christmas presents or if you just want a New Year clear out!

- Sunday 23rd June
- Sunday 18th August
- Sunday 13th October
- Sunday 8th December

Save the date: AGM 2019

Sunday 7th April
3 - 5.30pm
Centenary Hall, St Wilfred's
Way, Haywards Heath.

Committee

President

Dr Steve Dyer

Chair

Julie Unsted
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
Stephanie Barfield
Veronica Mamoany

Other ways of getting in touch...

www.mndwestsussexnorth.com

westsussexnorth@mndassociation.org

Facebook:
[mndwestsussexnorth](https://www.facebook.com/mndwestsussexnorth)

Twitter:
[@mndwestsussexnorth](https://twitter.com/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 2018.

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

MONEY RECEIVED

Money from activities:

Karen Maidment - Car Boot Sales	£200
Barbara Dente - WWII Vehicle Show at Ramsgate	£55
David Sheppard - Brighton Marathon (David Sheppard - grand total to date £806)	£31
Haywards Heath Golf Club (Al & Ben Turner - London to Brighton Bike Ride 2018)	£1,013
Al & Ben Turner - grand total to date £2,078)	
The Ark - Sale of Teas and Cakes	£44

Box Collections:

Norfolk Arms, Horsham	£26
-----------------------	-----

Donations and Gifts:

Mrs B. Noad	£25
-------------	-----

Other income:

Bank Interest	£100
---------------	------

MONEY SPENT

Financial Support for members & carers:

Home Adaptions	£1,200
Quality of Life Grant (two grants)	£2,000
Carers grant (two grants)	£1,000
Carers Resilience Programme	£150
Home Adaptations	£1,500
Contribution to Stairlift	£1,500

Expenses:

Visitors - Travel Allowance	£247
-----------------------------	------

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