

Newsletter

MNDA Parliamentary reception 2016

On Tuesday 18th October 2016 over 100 MND Association volunteers met with more than 55 MPs and Peers at a VIP reception, held at Church House, Dean's Yard, Westminster, with the aim of increasing MPs' understanding of MND and the issues that affect people living with the disease, their families and carers

Andy and Sandra Spriggs, attended as delegates from our Branch along with Dr Steve Dyer our Branch President. They were very pleased, not only to see so many people there, but also to have this opportunity to 'network' and talk to people from all over the UK enabling them to share views and experiences of



Pictured above: Sandra & Andy Spriggs with Jeremy Quinn MP

living with MND.

Penny Mordaunt MP, Minister for Disabled People, Work and Health, spoke to the attendees, telling them that "It's incredibly important for Members of Parliament, whether Ministers or backbenchers, to hear your stories. It helps us make better policy.....and get you what you need". Sally Light, CEO of the Association and Sara Ezekiel, who is living with MND and was recently named as Volunteer of the Year in the Third Sector Awards for her campaigning activities, were also present at this important occasion. Sally said that "It was wonderful to see so many of our amazing volunteers gathered together and for them to have the opportunity to share their personal experience of MND with MPs and Peers present". The reception also heard from author Dr. Jane Hawking, the first wife of Professor Stephen Hawking; Jane wrote the book behind the Oscar-winning film *The Theory of Everything* and remains a campaigner for people affected by MND. Jane urged politicians to ensure that people living with MND and their carers can access the financial support they are entitled to through the benefits system.

Discussions were held on the importance of Attendance Allowance and why it should be retained in its current form. The recent announcement by the Government of its intention to scrap re-assessments for Employment and Support Allowance (ESA) for those with severe lifetime conditions also came up for discussion, with the hope that people with MND will be exempt from these highly inappropriate re-assessments.



Pictured Above: Sally Light



Pictured Above: Dr Jane Hawking

Branch Fundraising Events

Fashion Show, Thursday 20th October 2016, Queens Hall, Cuckfield

A Fashion Show was held in aid of the Branch on 20th October – a complete sell out! Guests received a glass of Prosecco on arrival, with freshly made canapes and this set the tone for this very enjoyable and successful evening. The event raised a great total of £2,241.41!

Clothes were supplied by Jo Dennis, of Jo Jo Boutique in Cuckfield; Jo and her team put the outfits together for the models. Jo offered our supporters a 10% discount on their purchases and is donating a further 10% of the sales to the Branch.

Debbie at Hairworks in Cuckfield did the models' hair, and Ruth Corke of Profiles Hair and Beauty in Hassocks, did their make-up.

We had five wonderfully brave volunteer models; **Hannah Cottom, Jo and Leigh Stone, Carmen Eyre, and Amanda Norton (pictured right)**

Stephan Burn of Stephan Burn Photography travelled from London to be our photographer.

David Tingley, Editor of Cuckfield Life magazine supplied the lighting and played the music for the evening.

The canapes were supplied by Pat Colquhan as a donation (she made them all by hand and did a wonderful job!).

During the evening a raffle was held, with some great prizes; local businesses and companies were very generous with their donations.



Pictured Above: Carmen Eyre, Hannah Cottom, Amanda Norton, Jo & Leigh Stone



Murder in the Music – Who killed Nobby Twidler?

On 15th October, a very enjoyable and light-hearted evening of “murder mystery” took part in Horsham when Sue Sheppard organised for the Goring Region Occasional Players Ensemble to present their play “Murder in the Music”. An audience of over 80 people from near and far, including several people who had no connection with MND but who had seen the local adverts, were duly entertained by the 10-strong members of GROPE.

The play was set around an ageing 70's band, The St Cleve City Rockers, on a reunion tour to their home town. With cast members such as Juan Chord (Guitarist), Tim Pani (Percussion) and the famous Faye Kinnit & Aleisha Sober as singers, the audience knew they were due to watch an evening of music related puns and characters straight out of Spinal Tap!

After several false leads, false musical ability and false accents, the dreaded murder took place and the audience were given the ability to question those left on the stage as to where, why and what they were up to. Eventually, after a tie-breaker question a prize was given to the winning table for guessing the correct killer.

During the intervals a delicious Fish and Chip supper was served and raffle tickets were sold which boosted the final total to just under £840.00. A further £500 has been donated by the Horsham Freemasons for the event.

Our grateful thanks go to the members of GROPE who donated all their time and effort into providing the evening free of charge and to everyone who attended and joined in the fun. We were also grateful to Jeremy Quin MP who joined us on what must be one of his rare free weekends.

Well Done Charlie!



London to Brighton Cycle Ride – Charlie hits the saddle

It had been six years since my last physical fundraiser for MNDA, the London Marathon in 2010. I decided a new challenge was needed; the small matter of 55 miles from London to Brighton seemed to fit the bill. I therefore found myself unloading my bike from the car at Clapham Common early on the morning of Sunday 11th September.

The weather forecast was for perfect cycling weather and for once they got it spot on. What ensued was a three and a half hour jaunt through south west London, Surrey and Sussex. The views were tremendous, especially at the summit of Ditchling Beacon (a climb completed without stopping) as were the comments and conversations with the other participants, some 3,000 like-minded individuals. Along the way there was a short stop to refuel at the Ark and catch up with other MNDA fundraising riders and then it was onwards to the finish on Madeira Drive for a coffee and ice-cream in the sunshine.

I raised a total of £530. Many thanks for those who chose to support my endeavours.

Pictured Left Charlie Sheppard

Hurst Festival , Danny House, New Way Lane, Hurstpierpoint.

Saturday 24th September 2016.

The Plaegan Piano Trio, with Helen Sills (violin), Michael Nebe (Cello) and Alan Brown (piano), gave a performance as part of the 2016 Hurst Festival. The Trio takes its name from the Saxon word meaning 'joyful activity' and was first established in 1978 as a piano quartet. They have performed extensively throughout the UK, at major venues, and given concert tours in Germany.

The programme that evening consisted of Mozart's sparkling Piano Trio, followed by Dvorak's 'Dumky' Trio which contrasts melancholy Czech folk melodies with exuberant dances. The programme concluded with Mendelssohn's ever-popular Trio in D Minor.

A retiring collection was made in aid of the Motor Neurone Disease Association and raised £487.



Pictured Above: The Plaegan Piano Trio

Dates for 2017

Branch Socials will be held at The Ark in Turners Hill.

From 3.00pm—5.00pm

Sunday 26th February

Sunday 18th June,

Sunday 20th August,

Sunday 15th October, and Sunday 10th December

The Branch AGM will be held at The Redwood Centre (Haywards Heath Age UK) from 3.00pm to 5.00pm on

Sunday 2nd April 2017



The annual Quiz Evening was held on 12th November at St. Francis Social Club in Haywards Heath. 14 teams of 6 took part in what was – as always – a very enjoyable evening, complemented by a tasty supper.

Our thanks must go to everyone who provided the food for the evening and to the Quizmaster, Adrian Carter, who did his usual brilliant job of setting the questions, and who was ably, and energetically, assisted this year by Edward Carter.

The raffle had some very good prizes to be won, thanks to the generosity of the donors and overall the amount raised for the Branch was £977. A heartfelt 'thank you' to everyone who attended this very popular fund-raising event, and we look forward to seeing you all again next year.

Running for Team MND at this years Royal Parks Half Marathon on Sunday 9th October were (pictured from left to right) Victoria Bracey, Tom Bracey, David Williams & Ellen Bracey. They raised a total of £1,760.00. So a big Well Done! They were running in memory of their uncle Maurice, who passed away in April 2016 after a short battle with MND.



Future Fundraising Events

Horsham Quiz Night

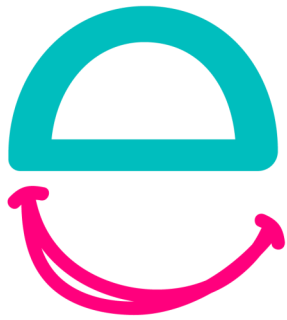
Saturday 18th February 2017 from 7.30pm at The Barn, The Causeway, Horsham
£10 per person to include supper, please bring your own drinks. Maximum of 6 per team. Tickets from Andy Spriggs: andyjspriggs@tiscali.co.uk

A donation will be made to St Catherine's hospice

Horsham Street Collection

Saturday 3rd June 2017—Please let Andy Spriggs know if you can volunteer.

Do you shop online? You can help us raise funds



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feel good shopping

amazon.co.uk

John Lewis

M&S
EST. 1884

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Booking.com

TESCO

Expedia

Argos

Did you know that whenever you buy anything online—from your weekly shop to your annual holiday—you could be collecting free donations for our branch?

There are over 3,000 shops and sites on board ready to make a donation, including Amazon, John Lewis, Aviva, The Trainline and Sainsbury's – it doesn't cost you a penny extra!

It's as easy as 1, 2, 3...

1. Head to <https://www.easyfundraising.org.uk/causes/mndawestsussexnorth/> and join for free.
2. Every time you shop online, go to easyfundraising first to find the site you want and start shopping.
3. After you've checked out, that retailer will make a donation to your good cause for no extra cost whatsoever!

There are no catches or hidden charges and MNDA - West Sussex North Branch will be really grateful for your donations.

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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 2016.

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

Money from activities: -

Liz Carter - Brighton Marathon £160

(Grand total to date £867)

Mark Streeter - Round the Island Yacht Race £1,580

Barbara Dente - Stall at Local Event £66

East Grinstead Rotary Club - Talk by Stephanie Barfield £100

Midhurst & Petworth Inner Wheel - Talk by Andy Spriggs £100

Lizzie Sawyers - Charity Ball £2,022

Kay Molloy - Bake Off £200

Ruby' - Ruby's Live Stream Gaming £1,550

John & Carol Rieley - Sale of Sweetpeas £220

The Ark - Sales of Tea and Cakes £53

Donations and gifts: -

Waitrose - Corporate Donation £560

Ian Weatherston £500

Donations and gifts in memoriam: -

In. mem Maurice Bracey £703

Other income: -

Bank Interest £23

Total Income £7,837

Financial Support for members:-

Quality of Life Grants (3 individuals) £1,500

Contribution to Planters £100

Contribution to Stairlift £600

Bio-bidet £857

Contribution to Adapted Vehicle £1,000

Contribution to Adapted Vehicle £1,000

Predictable Communication App £120

Predictable Communication App £120

Respite Care £1,000

Lightweight Wheelchair £341

Total £6,638

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 number
change**

**The new number is
0808 802 6262**