

Newsletter

Welcome our new Branch Chair - Julie Unsted!

After some time searching, our Branch is delighted to announce that we have a new Chair! Please all welcome Julie Unsted.

Some of you may well have seen and spoken to Julie over recent months while she has been getting to know the Branch, and it is with great joy we can announce that Julie was accepted as the Chair of the West Sussex North Branch at the AGM in April.

For 12 years Julie lived in Bahrain before coming back to the UK. Working from the age of 21 as cabin crew for Gulf Air, before eventually becoming Cabin Manager.

These days, Julie currently works part time for a media company 'Ticketmedia'



who produce transport tickets and sell the advertising space on the reverse.

She first became aware of MND when her sister-in-law was sadly diagnosed and passed away from the disease. Recognising the real need to raise awareness and to help families living with and having experienced MND, Julie reached out to help those in her local community.

So when you next see Julie, please say hello and introduce yourselves. And if you need a few topics of conversation to get things going, Julie very much enjoys her garden, walking her miniature labradoodle, Bonny, cooking, baking cakes and travelling.

Finally, a huge welcome to the Branch and we all look forward to your enthusiasm, support and dedication to the Branch.

Awareness Month

June will be national MND awareness month.

What are you doing to help raise awareness?

We've had the Ice Bucket Challenge, followed up by the 'Last Summer' campaign over the last couple of years for Awareness Month.

We would love to know if or what you have planned to help during this month. From Bake Sales, to Balls, tea parties, Boot Sales and more.

Get in touch and let us know what you are up to. We can support, promote or advise you, as you wish.

Long-Service award for Chris Sheridan

Anyone who has had the pleasure of working with, knowing or being supported by our Vice-Chair and long-standing Association Visitor, Chris, will know you cannot doubt her enthusiasm or commitment to the Branch over the years.

Now having reached the milestone of volunteering for the branch for over 11 years, Dr Brian Dickie, Director of Research Development from National Office gave Chris her long-service award at the AGM in April as a thank you from everyone.

I'm sure everyone from the Branch, past and present, would want to also extend their thanks and gratitude for all of Chris' hard work to supporting those with MND.

Thank you Chris!



Support the Round the Island race 2016, 2nd July



Now in his fifth year of taking part in the exhilarating and exciting Round the Island race, this year Mark Streeter and his crew are taking part to raise funds for the Branch, in memory of Mark's father who passed away from MND.

The Round the Island race takes place on the 2nd July this year and is one of the world's largest yacht races in the world with over 1,700 boats taking part and 16,000 sailors. It looks as though it gets pretty crowded as they all go around the Isle of Wight!

This race is the fourth largest participation event in the UK, following only the London Marathon, the Great North and the Great South Runs.

This year crew (pictured right) are - back row: Anne Marie Stewart, Paul Faircloth, middle row: Mark Streeter and Andy Cox. Andy's daughter, Annie (pictured) will help with the celebrations once complete but won't be made to work on-board during the race!

Please support Mark by donating here and do give generously: <http://uk.virginmoneygiving.com/team/BelleMarie>



Branch AGM and Research Update

This year's Branch AGM was held at Clair Hall, Haywards Heath in April.

All of the existing Committee members agreed to stand again for their positions and were voted in, plus we gained a Chair!

The update from Vice-Chair, Chris Sheridan, explained how the branch is now supporting more people than ever before living with MND. While Mike Abbott, our Treasurer, provided the accounts that demonstrated the vast majority of the funds raised for the Branch go directly to those living with or caring for those with MND.

After the Branch's business was complete, Dr. Brian Dickie, Director of Research Development at National Office gave a very informative, interesting and accessible talk about the current research programmes, partly funded from the Ice Bucket Challenge money. It was really exciting to hear about the de-



velopments, learnings and international co-operation to find treatments and a cure for MND

The first research project was called Project MinE, which is one of the biggest studies currently happening in the world on MND. This is researching the causes of MND through genome sequencing, which would have been impossible to do even a decade ago.

The second project uses the DNA bank, to try to 'clear the memory of cells' i.e. convert them

into stem cells, so healthy motor neurone cells can be created instead. Another project is called AMBROSIA with the aim of predicting how MND will develop in order to allow better care plans to be created for each patient. The fourth is a drug test, after having discovered a cancer drug effects motor neurones. This study aims to understand its real effects on MND and better understand Riluzole too.

Brighton Marathon run for MND

What do Zoe Ball and our Branch Secretary, Liz Carter have in common? They were both raising funds for the MND Association at this year's Brighton marathon but Liz was a bit more camera shy!

On Sunday 17th April 2016, Liz ran the Brighton Marathon for the third time. Having been quite vocal about the fact she didn't enjoy it the last couple of times, you might well ask why she volunteered to do it again. And in Liz's own words:

"It's a great way to raise money for the branch and I wanted to settle the issue of the annoying extra minute. For many years I have wanted to be able to say I can run a sub four hour marathon. To date I have run 4.03 and in 2013 I so



very nearly did it with the most frustrating time of 4.01!

Well I thought that was frustrating, until this year. This year I got tantalisingly close with a finish time of 4 hours and 34 seconds arrrgggghhhh!

The day was amazing with so much support for MND. Zoe Ball started the race and was with a crowd of MND

supporters at mile 23.

For once I haven't said 'never again'. I'm not done with that marathon distance yet....."

With gift aid Liz thinks she has raised over £900 for the Branch. Thank you to everyone who sponsored Liz and a special thank you to the anonymous donors, you know who you are.



Dates for the Diary

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

- Sunday 12th June
- Sunday 21st August
- Sunday 16th October
- Sunday 4th December

Fashion Show, 20th October—details to follow!

Date for the next Quiz Night!

Put the date on the diary now! Always a popular event that raises a lot for the Branch and is a lot of fun as well, so you don't want to miss it.

The next Quiz Night will be on **Saturday 12th November** at **St Francis Sport and Social Club, Haywards Heath.**

We'll be giving you details shortly on how to book your places, so watch this space!

Predictable App - giving a voice to someone unable to use their own

Losing your voice due to MND is incredibly difficult, from a practical, personal to emotional perspective. This is why support and care for this element of MND has been a key feature of both the national and local campaigning - 'Don't Let Me Die Without A Voice'.

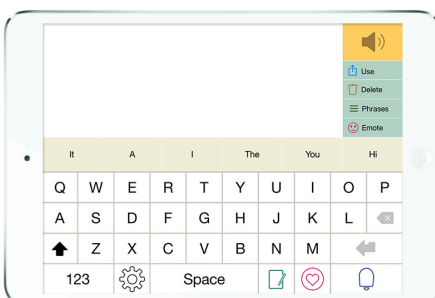
New technologies are making big, relative, improvements in the care and communication aids available. There is one in particular though we wanted to bring to your attention as it may be useful for some members.

Predictable, created by Therapy Box, is specifically designed for those with good cognitive function but have lost the ability to speak. An app for iPhones and iPads, it can 'bank' your voice and/or create a synthetic version where you have control of the pitch and accent. Simply typing in your message, facili-

tates the word prediction and the app then learns your patterns of speech and behaviour. The app costs £119.99 from the iTunes store.



To find out more visit: <http://www.therapy-box.co.uk/predictable.aspx>



Fundraising event successes

Horsham Quiz:

This year the Horsham Quiz raised £500 for the Branch, which is a fantastic amount. Always well supported but this year surpassed itself!

East Grinstead Street Collection:

A huge thank you to the collectors, donors and Sainsbury's in East Grinstead, who together managed to raise over £525 for the Branch.



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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 first quarter 2016.

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

MONEY RECEIVED

Money from activities:

Bells of Hammerwood - Xmas Carols (in mem. Brian Emmett)	£145
Pound Hill WI - Collections	£69
Mrs Lesley Phillips & Friends (in lieu Xmas Cards)	£101
Andy & Sandra Spriggs - Quiz Night	£500
Andy & Sandra Spriggs - Book Sales	£103
John & Carol Rieley - Sale of Sweetpeas	£350
The Ark - Sales of Tea and Cakes	£15

Donations, gifts & gifts in memoriam:

Tim & Stevie Roberts - Donation	£300
Pat & Colin Bendall - Donation	£200
Gerald Reed - Donation	£50
Alan Lester - in mem. Brian Emmett	£250
Rosemary Yates - in mem. Brian Emmett	£50
In mem. Judith Bevan	£270
Brighton Road Baptist Church - in mem. Audrey Smallwood	£105
David Julian - in mem. Jean Julian	£500

Other income:

Gift Aid	£113
Bank Interest	£30

MONEY SPENT

Financial Support for members:

Contribution to Stair lift	£600
Bio-bidet	£857
Predictable Communication App	£120
Contribution to Adapted Vehicle	£1,000

Expenses:

Visitors - Travel Allowance	£372
Room Hire - Cowfold Village Hall (year)	£166
Room Hire - AGM	£74

Other:

Annual Transfer to National Office for care services and research	£7,650
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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