



motor neurone disease
association

West Surrey Branch

Newsletter - Winter 2016



The Wey south of Guildford in winter

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Registered Charity No 294354

View from the Chair

Well, what a year it's been! Who'd have thought last winter that the UK would now be on its way out of the EU, and the next President of the USA is going to be Donald Trump? The old certainties have been proved to be shakier than most of us thought, and the future is unpredictable. These massive changes have been accompanied by some pretty nasty discourse, and divisions have run deep. It's been refreshing to regularly meet members of the MND family who are dealing with much more serious problems with great dignity, courage and concern for others, and for those of us privileged to know these amazing people, faith in humanity is restored.

However, whatever we humans do to each other in our self-important little way, the world outside carries on turning and the seasons roll past. Unbelievably, it's nearly Christmas already! Our next open meeting will be suitably informal (see below), and one of our members living with MND will be 'topping the bill', so we hope to see you there if you can make it.

Meanwhile, may I wish you a Happy Christmas, and all the best for 2017 !

Best Wishes,

Bob

CHRISTMAS MEETING

Our next Open Meeting is on Wednesday 21st December, in the Education Centre at the Cathedral as usual .

We invited Eamonn Cann, who is one of our members living with MND to tell us all about his interesting career in the film business, but he offered instead to entertain us with his songs. He's appeared on the club circuit with his selection of Sinatra and swing numbers, so this looks like being a very special occasion, and he deserves our support.

There'll be Christmas drinks and nibbles as well, so please come along if you can!

MND ALERT WRISTBANDS

These state that the wearer has MND, and should not be given oxygen in the event of breathing difficulties, as it may increase retention of CO₂ and thus make things worse. They are now sent out with core guides to people with MND, but may also be ordered from MND Connect.

COMPUTER STUFF

Those who espouse modern technology and have access to the internet may have noticed our branch website has disappeared. We're working on a replacement, but we're not experts and have a lot of other jobs to do, so please be patient.

However, we do still have a perfectly serviceable Facebook page. Relatively few of us are young or brave enough to be involved in social media such as Facebook. You may be surprised to hear it isn't just something the youngsters waste their time on, posting pictures of their lunch, or pouting 'selfies' (why don't they just smile??).

Even respectable organisations like the national MND Association and many of its branches, blue chip companies, clubs and charities use it. Why? Because it's a free, global notice-board. This branch has a Facebook page for just this purpose; if there are changes to (for example) the venue of a meeting scheduled to happen the next day, we can pop a notice on Facebook and it's there in seconds; we don't need to spend the Branch's money on phoning everyone!

It's also easy to put up photos and video clips of interest.

If you still recoil from this sort of thing, do pluck up courage to have a look sometime - get a grandchild to help if necessary!

Our Facebook address now matches our new name;

www.facebook.com/MNDAWESTSURREY

N.B. CATHEDRAL PARKING . .

If you come to a meeting by car, it's very important that you log your car details in the machine in the entrance lobby of the Education Centre. To counteract excessive use of the grounds for parking by people not on Cathedral business (commuters, shoppers etc), the Cathedral authorities have instituted a two-hour limit, which is obviously not enough for attending our two-hour meetings. Bona fide visitors to these escape a fine if they log in as above.

We'll remind everyone at each meeting, and please don't fail to do it - we don't want you to get an £80 fine, especially as a Christmas present!

News

PAULINE FOSTER

We are sorry to report that Pauline passed away at the beginning of October. Sallie Bushen knew her for many years, and has kindly provided this appreciation:

'Pauline was a friend and volunteer to the MND Association, South West Surrey Branch. She had served on the Branch Committee for 14 years, giving her dedication and compassion to people living with motor neurone disease till 2009, when she had to retire for health reasons, although still joining in the various branch activities where she could.

The Branch will remember Pauline as a kind and passionate person, of her great courage with her own problems. She will be greatly missed by so many who were privileged to have known her within the charity.'

On a personal note, I remember the Bingo evenings and Beetle-drives that Pauline used to organise for us. I wasn't an aficionado of either at the time, but the evenings always turned out to be fun, and Pauline was the expert who knew the rules and kept us all in order with firm but kind good humour. Latterly, her health was failing, but she did drop by our stall at the Cranleigh Carnival last summer for a chat, and it was good to see her.

She had been a valued member of the Branch since the start, and as Sallie said, served on the committee for many years. Her contribution was enormous.

Thank you Pauline.

'REGIONE BASILICATA' DANCE

The family of one of our pwMND hails from Italy, and help run a club for ex-patriots in the Epsom area. Originally the group was formed of people from the Basilicata region in the south, but now they have members from all over Italy.

Twice a year they hold fundraising dinner-dances, the proceeds of which are donated to all sorts of charities. The most recent event was on 22nd October, and our branch was delighted to be selected as one of the beneficiaries. Our Hon Chairman had the onerous task of attending the evening, eating Italian food and drinking the wine - a tough job, but someone's got to do it! Fortunately, his companion drew the line at joining in the dancing; the Chairman trying to dance is not a pretty sight! (Imagine Mr Bean's Grandad on speed . . .)

(Continued on page 6)

AEROBILITY

After having the first attempt called off because his personal pilot went sick, Paul Shrubbs finally got airborne on 22nd September. Judith rode shotgun to keep him in line. Judging by their grins when they got back, they enjoyed it!



If you're living with MND and you fancy getting a bird's eye view of your local area, and even having a go at flying the aeroplane yourself (under supervision of course!), have a word initially with Bob.

More information may be found on the Aerobility website:

<http://www.aerobility.com>

SAILABILITY

If flying's not your thing, but you've always hankered after sailing a small boat, and given up the idea after MND arrived, think again - there are sailing clubs that can arrange this for you. One such in our area is Frensham Ponds Sailing Club, who operate a 'Sailability' scheme. For more information, see:

<http://www.sailfrensham.org.uk/index.php/sailability/welcome-to-sailability>

RIDING FOR THE DISABLED

This is a well-known charity, but it isn't quite so well known that it also incorporates carriage driving, which may be more appropriate for people with MND. There are several stables in our area that provide these facilities.

<http://www.rda.org.uk/> has more.

STREET COLLECTIONS 2016

Many thanks to all who took part in our street collections this year. Results were mixed - some up, some down - and we added to our portfolio by venturing onto the streets of Staines on Thames for the first time. The total raised from all venues was £4482.11, which was down on last year's record-breaking sum, but several of the collections were hampered by bad weather.

Our first attempt at Staines was in the nature of a reconnaissance, and one of the things we discovered was that a large part of the most lucrative-looking parts of the town were privately owned and therefore needed separate permissions from the usual municipal one. A few of us were politely asked to 'move on' from these areas, but we will do the extra paperwork next time to avoid this problem arising again. This was one of the occasions when it was very wet all day, which did nothing for the result.

There are some towns with compact centres which can't cope with many collectors; after all we don't want to annoy the locals by popping up every few yards! Most places are not like that, and if we had more volunteers, the work could be spread more thinly, and the Old Faithfuls wouldn't be called upon to go above and beyond the call of duty so much. If you're still a collecting virgin, please consider having a go next summer - it's not that bad meeting the Great British Public!



MNDA CHRISTMAS CARDS

*Last chance to get your
MNDA cards!*

We'll have them at the Drop-in on Wednesday 7th December and the Open meeting on the 21st.

If you find you've got a card from someone you didn't expect to hear from, why not stick one of our cards through their door at the last minute?

You can do the same for people who have forgotten *you* - a card on their doormat when it's too late to respond will definitely give you the Moral High Ground!

COMBINED CHARITIES CHRISTMAS FAIR

We always attend this event in the historic Guildhall in Guildford High Street. This time it was on a Sunday (20th November), so there were concerns that not many of the public would be about. However, nowadays Christmas seems to begin somewhere in mid-summer as far as shopping is concerned, and the town was very busy, with many shops open. We never expect to make much money here, but the awareness raised is always worthwhile, and we get to meet the current Mayor and make sure he knows a bit more about MND and any problems in local care by the time he escapes from us!

We were also honoured(?) by a visit from a well-known local eccentric who informed us forcefully that MND, other diseases, wars and pestilence generally could all be cured by a vegan diet. If only it were that simple . . .

RAILWAY STATION COLLECTIONS

As an experiment, we are planning to start collections at various stations in our area next spring. You'll be relieved to know that these will not require many volunteers, but there may be occasions when the usual small force of stalwarts needs to be reinforced.

Of course there is a pile of paperwork to be completed before all details are in place, and our Hon Sec Joan is valiantly battling with this. More news later.

CEO's APPEAL

Each year Sally Light asks branches and groups to contribute to certain functions in the Association she feels need particular support. This year, the choices were:

- Supporting people with cognitive changes and FTD
- Using the NICE guidelines to audit service quality
- Funding a single point of contact for wheelchair or AAC problems
- Welfare benefits advice
- Association 40th Anniversary memories project

On this occasion we decided to contribute £5000, to be used at the Trustees' discretion.

**Financial Update
1st September to 30th November 2016**

Static Collecting Boxes

The collection boxes located in West Surrey's shops and taverns yielded a total £ 93.11 made up as follows;

Harper's Photographic, Woking	£ 31.44
White Lodge Farm	£ 16.58
Nisa, Bramley	£ 45.09

Donations/In Memory

Since our last Newsletter donations totalling £ 12.40 have been received.

Street Collections

To all those who helped with our street collections please accept a sincere thank you from the West Surrey Branch. At Staines on Thames donations totalled £ 369.49 resulting in a grand total of £4,482.11 being collected on the streets of West Surrey during 2016.

Other Activities

As always we are very grateful to those individuals and groups who organise their own fund raising events to support the MND Association. Recently a grand total of £1372.50 has been raised.

The Italian evening (see page 3) resulted in £1000.00 of the funds raised being donated to our Branch.

Roger Dyer's earlier events this year have now been enhanced by £250.00 from The Charities Trust. Our Branch Autumn raffle yielded £35.00 and Model Bus sales total £87.50 to date.

In addition to the above, MNDA Christmas cards etc. have been sold at various locations including the Haslemere and Guildford charity fairs. Sales of Christmas cards, of which the Branch receives a small percentage, currently total £393.15. A further £108.00 was raised from sales of hand crafted Nepalese bags and purses and this will provide support for the MNDA in Nepal.

Care & Equipment

A total of £1078.10 has been spent during the last three months to benefit people in our area in need of care and special equipment.

Thumbs Up Club

Our lucky winners were:

September:	T Spinks	(006)	£ 50.00
	P Foster	(095)	£ 30.00
	M Dean	(185)	£ 25.00
	J Haywood	(046)	£ 20.00

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MODEL BUSES

Alvin, our Treasurer knows everything there is to know about buses. Recently he found a manufacturer of die-cast models which was ceasing trading, and acquired a large number of bus models. He then had tiny MND Association adverts printed and stuck to the sides of the models, and even made presentation boxes for them! He's offering these unique models for sale at £12.50 each to raise funds for the branch.

We're extremely grateful to Gilbow (Holdings) Ltd who provided the models and to Headline Print & Design of Woking, who provided the adverts - and of course to Alvin for thinking of this project and spending enormous amounts of time preparing the models. What about buying a bus for The Man (or Woman) Who Has Everything? Buses are available in a range of types and liveries, so it's likely he can find you one which has some particular relevance to you. He found me this red London Transport RT type bus which I used going to and from school every day aeons ago - a real stroll down memory lane, and some money in the branch coffers!



.Actually, the model is much smaller than it looks in the photo above . .



Research latest

The rate of discovery of genes implicated in familial MND continues to accelerate, with another two this year. These are especially interesting as they seem to be implicated in the sporadic form as well, so could be crucial in future understanding of the disease.

Briefly, the most notable genes of interest are:

SOD1 discovered 1993, causing about 20% of cases of familial MND

TARDBP (TDP-43), discovered in 2008, accountable for 3-5% of cases of inherited MND

FUS, discovered in 2009, accountable for 3-5% of cases of inherited MND

C9ORF72, discovered in 2011, accountable for around 40% of cases of inherited MND

TUBA4A inherited MND gene discovered (October 2014)

TBK1 inherited MND gene discovered (March 2015)

NEK1 genetic changes linked to MND (*with and without a family history*) (July 2016)

C21orf2 genetic variation linked to those *with no family history* (July 2016)

Other genes have been discovered which have implications in smaller numbers of cases, making the total now about 30, most of which have been discovered since 2007. There is an interesting graphic showing the timeline of discoveries and the relative importance of each in the address given by Prof Dame Pamela Shaw at his year's AGM back in September. To catch up with this informative dissertation on many aspects of MND science, from an expert, see:

<https://livestream.com/eventstreamingcompany/mnda/videos/135503995>

'REGIONE BASILICATA' DANCE

(Continued from page 3)

The official job we had to do was to collect a cheque for a magnificent £1000, say a few words about MND and offer our thanks. The rest of the money raised went to the aid of victims of the latest earthquake in Italy, a very worthy and appropriate cause.

This was a very pleasant job, and the people were friendly and welcoming . . . and they certainly know how to enjoy themselves!

Coming up . . .

Wednesday 7th December

December 'Drop-in' Support Meeting
as always, Cathedral Refectory, from 2pm

7th - 9th December

27th International Symposium on ALS/MND
Dublin

There will be more than 35 hours of presentations from leading researchers into the nature and causes of MND. Keep up with the news on:

<http://www.mndassociation.org/research/international-symposium/symposium-live-2016/>

Wednesday 21st December

Winter Open Meeting
Cathedral Education Centre from 2pm

Winter Drop-in Meetings

- will continue every month unless the weather looks really, *really* bad on the forecast. It takes a lot to put our people with MND off!

Thumbs Up Club Winners (cont. from page 5)

October:	F E Fleeson	(101)	£ 40.00
	P Overton	(304)	£ 30.00
	E Godden	(087)	£ 25.00
	R Carnell	(240)	£ 20.00
November:	M A Few	(004)	£ 40.00
	J Tombs	(085)	£ 30.00
	R J Bennett	(102)	£ 25.00
	T Spinks	(006)	£ 20.00

If you would like to participate in the 'Thumbs Up' Club, please contact Sallie Bushen on 01483 274337 for a Share Number application form. Each annual Share is £12.00 payable either by bank Standing Order or cheque payable to MNDA Cranleigh Thumbs Up Club.

Alvin Hale, Treasurer

Can you help?

We always need more Super-people to help us to improve what we do, especially with **fundraising**. (Anything legal considered!)

We could also do with someone who can help with our website and social media.

If you have ideas and energy, and want to make a difference to people with MND now and in the future, please get in touch with anyone on the 'Who's Who' list opposite.

Are you living with MND?

.. Or do you know someone who is? Are they feeling a little solitary?

Informal 'Drop-in' meetings are held every month in the Cathedral Refectory, specifically for anyone with MND and their family. You are very welcome to come along to share your experiences, ups and downs, or just chat to friends over a cup of tea. First Wednesday of every month at 2.00 pm.

Open Meetings

*Guildford Cathedral Education Centre
2.00 to 4.00 pm*

Wednesday 21st December 2016:

Christmas Open Meeting

**'The Sinatra Experience'
and
'Legends of the 50s and 60s'**

by
Eamonn Cann

Plus Seasonal Drinks and Nibbles

How to find us

By car: Stag Hill, Guildford, GU2 7UP
Adequate free parking
but see important note on page 2 !

By train: 10 min walk from Guildford Station

By bus: There are no public bus routes that come right up to the Cathedral; however, there are several routes that stop at the bottom of Stag Hill, leaving a 5 minute walk up the hill to the Cathedral. Get off at the top of The Chase.

Who's Who in West Surrey Branch

Chair:	Bob Hodgson	01483 893588
Newsletter Editor:	“ “	
Vice Chair:	Mary Carr	01483 419774
Treasurer:	Alvin Hale	01252 310962
Secretary:	Joan Hornett	01252 325851
AV Co-ordinator:	Lucia Woodward	01428 643459
Membership Sec:	Alison Husaunndee	01483 723645
Branch Contact:	Joan Hornett	01252 325851

Please note:

Things change between newsletters!

You can keep in touch with news and events by keeping an eye on our digital accounts which are usually updated every few days:

website: currently unavailable, but a new site is being worked on

Facebook: Please note the new address:

<https://www.facebook.com/MNDAWESTSURREY>

or twitter: https://twitter.com/MNDA_SWSurrey

National Office:

MND Connect 0808 802 6262

email: mndconnect@mndassociation.org

National website: www.mndassociation.org

tel: 01604 250505

