



motor neurone disease  
association

## West Surrey Branch

## Newsletter - Summer 2017



#MyEyesSay campaign this month (page 2)

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Registered Charity No 294354

## View from the Chair

June is MND Awareness Month. This year, the Association has created a campaign called

**#MyEyesSay.**

The only parts of the body that always seem to remain unaffected by MND are the eyes; if your eyes were all you could move, what would you say with them? The stories of three people with MND are featured, and the picture on the front of this newsletter is of the eyes of Gemma, one of the three. She was diagnosed at the age of just 29. We are invited to use a mask with an eye cutout to help us imagine what it's like to have advanced MND, and what we'd like to say via our remaining eye movement. A mask template can be downloaded from the main website, and you upload a picture of yourself wearing the finished article (with your chosen quote written on it) back to the site. These will be added to a big collage to be broadcast on Global Awareness day, the 21st June.

It sounds a lot more complicated than it is. I intend to have a go, although my eyes in close-up won't be nearly as beautiful as Gemma's, especially after a heavy night!



The 21<sup>st</sup> happens to be our Open meeting day (see below), so why don't we all do one of these at the meeting, get John to take the pictures, and we'll upload them that evening?

We'll also have some seasonal refreshments - but you'll miss out if you're not there!

We hope to see you on the day.

Best Wishes,

*Bob*

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## SUMMER MEETING



Our next Open Meeting is on Wednesday 21st June, in the Education Centre at Guildford Cathedral.

Our speaker will be Pollymarch Mather, Collaborative Commissioning Manager at Surrey Downs NHS Clinical Commissioning Group.

Strawberries and Cream, and Fizz will be available (plus juice or tea/coffee of course!)



*MND Association*

## AGM and Annual Conference

Saturday 8<sup>th</sup> July

Radisson Blu Hotel, East Midlands Airport

The main speaker will be Prof Ammar Al-Chalabi, who is always well worth listening to. To register, go to:

[www.mndassociation.org/news-and-events/events/conferences/agmandannualconference/](http://www.mndassociation.org/news-and-events/events/conferences/agmandannualconference/)

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## N.B. CATHEDRAL PARKING

**Another reminder . . .**

***If you come to a meeting at the cathedral by car, it's very important that you log your car details in the machine in the entrance lobby of the Education Centre, on the counter in the Refectory, or in the shop.***

***We'll remind everyone at each meeting, and please don't fail to do it - apparently the fine has gone up to £90 !!***



Patrick 'The Optimist' Joyce was a talented artist who became the MND poster boy of 2010. Soon after his diagnosis two years before, he set himself the target of producing 100 portraits of significant people in the MND world in the UK. Unfortunately, the disease robbed him of the ability of achieving more than 20 of that total. One of the completed portraits was of the late Roy Redford, who ran many marathons to raise money for this branch.

In spite of the disappointment, he pressed on with all sorts of projects, including writing a regular blog which described his life as the disease progressed; not in a downbeat way, but with great good humour sometimes mingled with sadness when for example his friend Alistair Banks, who succeeded him as the face of MND in 2011, passed away.

His father David had built a light aeroplane in the 90s, and they hatched a cunning plan to raise money for the MND Association by attempting to visit and photograph all 119 islands named on the standard half million scale (1:500000) aviation charts of Britain and Northern Ireland . . . *in one day*, as part of the Dawn to Dusk Challenge 2010. This would be quite a challenge for David, given the vagaries of the British weather, and no less for Patrick, as he would have to sit in the aircraft for many hours as they ticked off the targets, with the minimum of landings for refuelling and 'comfort breaks'.



They managed it, covering 1703nm in 13hrs 05mins flying time, raised £13000 for the Association, and won a Royal Aero Club Silver Medal for their achievement. You can see a short film on:

<http://www.youtube.com/watch?v=DRlobPxXhnl>

and his (expired but still informative) Justgiving page on:

<http://www.justgiving.com/fundraising/halfmillionislands>

Later, he conceived a method of controlling electric wheelchairs using Eyegaze technology, and developed it along with his friend Steve Evans, who also had MND, and a small team of engineers. Basically it involves a clever electronic 'box of tricks' to interface between the standard Eyegaze unit and the wheelchair. Plans for it are now freely available on the net, and parts may be made using the small 3D printers now available at prices which are becoming more affordable. Only a couple of years later, there are paraplegics as well as people living with MND who, having lost the use of their hands, still have the mobility that a wheelchair provides.

The heading picture shows Patrick testing a prototype of the system. There is lots of information about this successful project on:

[www.eyedrivomatic.org](http://www.eyedrivomatic.org).

Occasionally, things went a bit quiet on the blog front, and one feared the worst . . . but then, up he would pop with another update, written in his funny and self-deprecating style. He seemed indestructible. Then the news broke in April that he had passed away. His wife Kathy wrote a moving tribute to him, and many of us reading it wished we'd had the pleasure of knowing such a fantastic, funny, imaginative, thoroughly inspirational human being.

*For a reminder of Patrick's campaign, go to:*

[www.mndassociation.org/news-and-events/awareness-campaigns/incurable-optimism/](http://www.mndassociation.org/news-and-events/awareness-campaigns/incurable-optimism/)

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*(Left) Europa G-XSDJ built and flown by Patrick's father David in the Dawn to Dusk Challenge and other adventures*

## News

### *ELECTROMAGNETIC FIELDS (EMF)*

*- do they create a risk of MND??*

Repeated exposure to low-frequency electromagnetic fields could increase risk of developing ALS, the most common form of the MND, according to a research project at Utrecht University.

'Pilots, welders, electricity network engineers, even tailors and seamstresses who lean over sewing machines all day' could be at risk according to the report, but Professor Christian Holscher, from Lancaster University, said the results should be interpreted with caution, adding: 'The effect of extremely low-frequency magnetic fields on ALS development is not clear.

'The trend is only just statistically significant, and with such low numbers, it may well be a false positive.'

Brian Dickie, director of research development at the MND Association, said: 'Any such effect is a very subtle one.

'It does not mean that exposure causes motor neurone disease.'

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### *'FATHoM'*

The first meeting of FATHoM (Families for the Treatment of Hereditary MND) was held on 18th April, at the Saïd Business School, Oxford University. A full day of presentations on Genetics and Genetic Testing, Research and emerging Future Treatments was followed by a lively Q & A session. Delegates went home exhausted but enthused!

Leaders in MND research, including Profs Kevin Talbot and Martin Turner of Oxford, and Chris Shaw of King's College London worked hard to explain their latest work to a room full of amateurs who had only experience of familial MND in common. The impression left was of optimism; the amount of work particularly in genetics, is increasing, and the number and characteristics of genes implicated in fALS (familial ALS) is increasing both in quantity and quality.

Significantly, Prof Shaw ended his presentation with the remark that he started his career in MND research 25 years ago thinking it would be his life's work. Now he thinks he'll be studying something else for a while before he retires!

### *BENEFITS ADVICE*

We have a stock of business cards and leaflets promoting the Association's benefits advice service. They will be available at Drop-in support meetings and Open meetings, but if you can't get to any of these, have a word with your AV or contact Bob.

More information is available on:

[www.mndassociation.org/benefitsadvice](http://www.mndassociation.org/benefitsadvice)

or phone 0808 801 0620

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### *RAILWAY STATION COLLECTIONS*

We started these as an experiment this spring. Initially, only four stations, with a maximum of two collectors each. Perhaps surprisingly, the commuters didn't seem to mind being relieved of their cash in aid of MND, even when rushing to work!

As you'd expect from this small-scale experiment, the financial results weren't overwhelming, but they were encouraging enough for us to develop them into a bigger operation next year. Your committee will need reinforcements here and there, so if you don't mind getting up early in a good cause, look out for the details of the 2018 exercise later!

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### *AUTUMN OPEN MEETING*

*Something different this time - we're going to try having the Open meeting at the weekend.*

The choice of time and venue is always a compromise, and at the moment, the weekday afternoon slot is fine for retired supporters as well as people living with MND. Moving to the weekend would also make it possible for supporters who work for their living to come along, but this would not be possible at the Cathedral.

Recently, rooms at Surrey Research Park became available for use by genuine charities in the evenings and weekends, so we're investigating these facilities. The provisional date for our first meeting there is

Sunday 24th September, from 2 to 4pm

Details of location, speaker etc will appear later on our Facebook page and in the next newsletter

## Coming up

### REMAINING STREET COLLECTIONS 2017

Saturday mornings, normally 0930 to 1300

17 June	Cranleigh
1 July	Haslemere
15 July	Guildford
22 July	Camberley
5 August	Woking
12 August	Staines
16 September	Aldershot

We need more volunteers to spread the load and increase the money coming in. To book yourself in, call Mary Carr on 01483 419744.

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### OL' BLUE-EYES IS BACK - again!

Last Christmas, branch member Eamonn Cann sang for us at our Open Meeting, and the next night he repeated his tribute to Sinatra at 'The Greyfriar' in Chawton, in aid of our branch.

Now, after moving house, he's going to have another go in his new local, 'The Barley Mow' in Shepperton.

He carries on singing in spite of living with MND, and deserves lots of support, so if you're in the vicinity, or can get yourself there specially, do come along!

So, remember . . .

#### Where?

'The Barley Mow'  
67 Watersplash Road  
Shepperton  
Surrey TW17 0EE

#### When?

Sunday 2<sup>nd</sup> July, 4.00 to  
7.00 pm



### SKYDIVE 1 !

Mary Carr's grand-daughter Chloe is bravely jumping out of an aeroplane at 12000 ft on August 17th, to raise funds for this branch!

Don't worry, Mary, she'll be wearing a parachute and accompanied by an instructor!

She will be setting up a Justgiving site where you can sponsor her; details of this will be published on our Facebook page.

### SKYDIVE 2 !

Kelly Hudson, who lost her grandmother to MND some years ago, is jumping out of another aeroplane for us later in the summer.

More details of how you can sponsor her will be published when we have them.

*How many of us would willingly leap out of a perfectly serviceable aeroplane a couple of miles up? Not for me, thanks, and I suspect not for most of us! These plucky girls deserve every bit of support we can give them, so keep an eye out for sponsorship details later, and tell your friends!*



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### CRANLEIGH CARNIVAL

This year's carnival is on Saturday 24th June. We'll be there, but this year our usual source of plants for sale will not be available.

If you have anything saleable that you're willing to donate to raise funds for the branch - plants or otherwise - please let one of the Committee know, or bring them along on the day. Thank you.

## Financial Update from 1<sup>st</sup> March to 31<sup>st</sup> May 2017

### Static Collecting Boxes

The collection boxes located in West Surrey's shops & taverns yielded a total £ 96.15

Little Market, Merrow: £ 5.34  
Nisa, Bramley: £ 90.81

### Donations/In Memory

Since our last Newsletter donations totalling £1,050.00 have been received.

### Branch Fund Raising

Our new venture of railway station collections during March & April proved worthwhile with a total of £484.26 being donated by commuters travelling from Godalming, Woking, Guildford and Aldershot stations. Our thanks go to the friendly cooperative staff of South West Trains during the chilly early morning periods. The 2017 Street collection season commenced with £436.39 collected by volunteers in Godalming. Our MNDA merchandise sales totalled £20.00 and the Branch Spring raffle yielded £64.00.

### Other Activities

As always we are very grateful to those individuals and groups who continue to organise their own fund raising events to support the MND Association. An amazing £4,626.10 has been received this quarter.

A Keep-Fit group from Staines raised £225.00  
Ros Bennet's Jazz Nite: £245.00  
Roger Dyer's various activities have yielded £841.10  
Petworth Darts League with Northchapel's Working Men's Club: £250.00. £1,245.00 has been allocated to the Branch resulting from Tony & Enza Militello's Bakeit & Artwork event which was held in January. Despite some occasional unwelcome showers, Mary Hainline's Open Victorian Garden 3 day event resulted in an astounding £1,820.00 being deposited in the coffers. A BIG BIG THANK YOU to all our fund raisers.

### Care & Equipment

A total of £ 1,514.10 has been spent during the last three months to benefit people in our area in need of care and special equipment.

## Thumbs Up Club Winners:

Our lucky winners were:

March:	A Hale	(293)	£ 50.00
	P&J Merritt	(028)	£ 30.00
	V Speers	(106)	£ 25.00
	I Brown	(237)	£ 20.00
April:	L Brewster	(044)	£ 40.00
	L Brignall	(228)	£ 30.00
	L Brignall	(133)	£ 25.00
	I Brown	(207)	£ 20.00
May:	F&DA Clark	(057)	£ 40.00
	C Gray	(160)	£ 30.00
	S McIntosh	(170)	£ 25.00
	R Hodgson	(167)	£ 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*

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### Coming up (continued)

#### *The MNDA SE Regional Conference*

will take place on 24th September in London, at the Doubletree by Hilton, in Hanger Lane, Ealing.

You may register on the main Association website, here:

<https://www.mndcommunity.org/conference-and-events/ce17rcse09>

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### YOUR EVENT HERE!

*We always need supporters who are willing to get wet, dirty, and tired in order to raise funds for this branch and for the wider world of MND!*

*If you have a good idea (and it doesn't have to involve getting wet, dirty or tired!), let us know and we'll help to develop your plan and offer support all the way.*

## Research latest

### **Radicava (Edaravone)**

- approved by FDA in the States for ALS

Excerpts from the 'ALS News Today' report:

"On Friday May 5th, the US Food and Drug Administration announced its approval of the drug known as 'edaravone' for the treatment of MND. This is exciting news! Edaravone is the first MND medication to be approved by the FDA in 22 years, since Riluzole in 1995.

The first treatment for amyotrophic lateral sclerosis (ALS) in more than two decades, Radicava (edaravone), has been approved by the U.S. Food and Drug Administration and will soon be available to patients.

The FDA decision, hailed by physicians and ALS advocates, brings hope to the ALS community that treatment development, after a long slumber, is again on the move."

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### **ANXA11**

A new addition to a list of genes that are related to development of ALS, the most common form of MND, has been discovered by researchers from King's College London. Dr Bradley Smith and colleagues screened genetic data of an unusually high number of people of European origin: 751 with inherited – familial – ALS (fALS) and 180 with non-inherited – sporadic – ALS (sALS). Detailed analysis of this data found that specific mutations in the ANXA11 gene are associated with around 1% of all fALS and 1.7% of all sALS cases.

While this may seem like a small percentage, (to quote the MND Research Blog), 'it is another great finding that can tell us more about the mechanisms of MND. Discovery of new genes is a very important first step that can take us closer to understanding how and why a gene causes motor neurones to die.'

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### **Positive early results for motor neurone disease drug discovered by BenevolentAI**

Early test results for a new drug candidate discovered by artificial intelligence (AI) that could potentially delay the onset of MND have been positive, raising hopes for those with the disease and highlighting the potential of the technology.

The study, carried out by The Sheffield Institute for Translational Neuroscience (SITraN), has assessed the efficacy of a drug discovered utilising London-based BenevolentAI's Aitechnology., And the research found that there were 'significant and reproducible indications' that the proposed drug prevents the death of motor neurones in those suffering from MND.

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### **ALSoD – ALS Online Genetic Database**

A new three year grant has recently been awarded to fund further development of a genetics database called 'ALSoD', which is the main library of information on the ever-growing number of genes identified as having implications in the development of the disease. The funding is provided from the ALS Association, the MND Association and PatientsLikeMe.

Managed by Prof Ammar Al-Chalabi from King's College London, the database has been co-funded by the ALS Association and the MND Association for many years, but this is the first time PatientsLikeMe have supported the project.

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### **The MND Research Blog**

- has just produced an article on 'How is tissue donation helping us to solve the MND puzzle?'

They go on to explain how difficult it is to study the living brain, and how post-mortem study can help in

- 1 Finding the causes
- 2 Understanding how MND develops
- 3 Confirming a diagnosis, and
- 4 Fighting back

Tissue donation is a very personal decision that needs to be thought through carefully. A newly revised information sheet for those considering donation is available on the MND Association website. See:

<https://www.mndassociation.org/wp-content/uploads/2015/05/I-Tissue-donation-January-2017.pdf>

## 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.

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## 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.

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## Open Meetings

**Summer Open Meeting**  
Guildford Cathedral Education Centre  
Wednesday 21st June 2017  
2.00 to 4.00 pm

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**Autumn Meeting - Provisional details**  
Surrey Research Park  
Sunday 24<sup>th</sup> September  
2.00 to 4.00 pm

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## 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

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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:

Branch Website: [www.mndawestsurrey.co.uk](http://www.mndawestsurrey.co.uk)

Facebook: Please note the new address:

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

or twitter: [https://twitter.com/MNDA\\_SWSurrey](https://twitter.com/MNDA_SWSurrey)

National Office:

MND Connect 0808 802 6262

email: [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

National website: [www.mndassociation.org](http://www.mndassociation.org)

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