



motor neurone disease
association

West Surrey Branch

Newsletter - Summer 2018



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View from the Chair

The passing of Professor Stephen Hawking in March was marked by an outpouring of respect and admiration from all parts of the world. Whether he stands quite with his illustrious predecessors Newton and Einstein will probably be debated for years to come, but to us in the MND world he was a wonderful ambassador and role model. It's been noticeable how more of the public seem to know a little about the disease now, whereas a few years ago they would know nothing if it had not touched their family or friends. Prof Hawking's high profile has no doubt played a large part in this.

We've just heard that Doddie Weir's 'My Name's Doddie' Foundation is to donate £400000 to Prof Chris Shaw's research team at King's College London. The retired Scottish rugby player, who was diagnosed last year, is devoting his time to raising awareness and funds, and the first fruits will help

KCL's research into gene therapy for sporadic cases. We wish them every success.

Our next open meeting, on Sunday 24th June, will incorporate the AGM, which was postponed from March. You'll no doubt remember the spell of Siberian weather which put paid to *that* cunning plan!

Dr Brian Dickie has kindly agreed to join us in our second attempt, and will travel down - in hopefully balmy summer weather - to tell us about the latest in research. He'll be well worth hearing, so please make every effort to come along. Coupled with a delicious spread from Avala Catering, and a glass of something celebratory, what could be better?

We hope to see you there!

Best Wishes,

Bob

SUMMER OPEN MEETING

and AGM

Surrey Technology Centre

Sunday 24th June, 12.30 to 3.30pm

Guest Speaker: Dr Brian Dickie

Director of Research Development

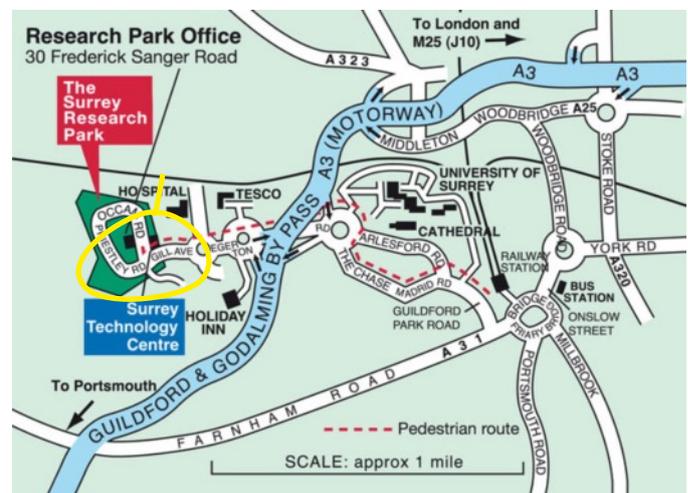
A light buffet lunch and drinks will be available from 12.30. This will again be provided by Nigel Husaunndee and his firm Avala Catering.

The formal part of the meeting will start at 1.15. The AGM will be kept as short as possible, and we'll then move on to a talk by Brian Dickie on the latest developments in research and the International Symposium in Boston last December. He will be covering different ground to that about which Belinda Cupid spoke last September, so it won't be a case of 'déjà vu' all over again!

After that, the Raffle, Thumbs Up Club Draw, . . . and more of Nigel's food!

Here again are details of the venue:

Room 8, Surrey Technology Centre,
40 Occam Road, Guildford, Surrey GU2 7YG



Please let us know if you intend to come along, so we have some idea of the catering needed.

Contact Alison Husaunndee by 18th June, on:

*email alison@husaunndee.com
or phone 01483 723645
(or any other member of the Committee)*

. . . and we'd be grateful if you could bring a Raffle Prize with you - thanks very much!

News

Mary Hainline's Garden Weekend

11 - 13th May

Once again, Mary opened her house and garden in Bramley to show her artwork. She kindly donates a portion of the proceeds to us, and we have a presence through all three days to chat to visitors, raise a bit of awareness, and of course sell them raffle tickets!

This year, the total raised is currently a fantastic £1517.05, and there's a bit more to come. Last year's record included a generous one-off donation of £500, so discounting that, we've done a little better this year.

Many thanks to all who helped, and of course to Mary and Doug for helping us in this way every year.

Hickstead Tickets

Once again, we have acquired some complimentary tickets for this summer's events at the Hickstead show-jumping grounds in Sussex. The meetings and days available are:

The Al Shira'aa Hickstead Derby Meeting

- Fri 22nd and Sat 23rd June only

(but note the first day, Thurs 21st is free entry for all)

The Longines Royal International Horse Show

- Thurs 26th and Fri 27th July only

If you'd like one ticket, or a few, contact Bob.

First come, first served!



Short Story Competition

Fancy yourself as an author? Why not enter this short story competition in aid of the MND Association?

Publishers Claret Press are organising the competition as one of their authors, Sarah Gray, is living with MND and is anxious to do her bit to raise funds and awareness.

It could mean fame and glory for you too!



More details and an entry form on:
<https://www.claretpress.com/mnda-short-story-competition>

Maggie Monteath honoured

One of our branch AVs, Maggie recently received her 10 year anniversary certificate from RCDA Jane Giles.



Congratulations Maggie, and thanks for your decade of work for people with MND!

News

Holiday to India with MND

by
Lisa Milella

I have been to India many times but never as a tourist so decided I would brave another trip to such a colourful, interesting country that has been a special part of my life. My previous trips to India have been with International Animal Rescue to treat dancing bears and tigers both in the North, near Agra, and also in the south near Bangalore. I knew that it would be a challenge - the last time I was in India I was still walking, with a stick, and needed help getting out of chairs and things like that, but arranging this trip I knew I would be needing full time care and be fully wheelchair-bound. I have never travelled with my powered wheelchair as I have been unsure about reliability and what to do if things go wrong. At least with a manual chair people can help you get over a little step if need be, and it can fold up into the back of the car which isn't the case with the powered chair. Also, I'm not sure how easy it is to fly with the powered chair and knew that the places I wanted to see would involve some internal flights so I didn't want to take a chance. The internal flights were better than expected - it's always a relief to see your wheelchair at the other end! One of the budget airlines that we flew on actually had special bags that the wheelchair was put into at check-in, together with the footrests and a separate pocket for the cushion, better than my experience with some of the European airlines! One challenge though was the ventilator. Every airline was unsure about the ventilator and had raised concerns about it, and me, each time we checked-in. I had a copy of the medical clearance to fly that Virgin Atlantic had requested for the international flight which seemed to suffice for each airline.

I booked all of the land arrangements through a company called Enabled traveller, based in India. They sourced suitable vehicles, accommodation with disabled access and wet rooms, were able to get special access to drive right up to some of the tourist attractions, knew the best disabled route around palaces and temples, and went out of the way to ensure that I was able to have the holiday I wanted.

At one Jain temple, wheelchairs were not allowed, so I was transferred to a fold up garden chair that had been modified with handles and two of the workers carried me around this spectacular marble temple!

At the Amber Fort in Jaipur we learnt that the first wife of the Maharaj at the time wanted to be treated and seen differently from the other wives so was wheeled around the Palace, resulting in this being a tourist attraction where being in a wheelchair was no problem at all.



*Lisa with her parents Gail and Don
at the Amber Fort*

I had always wanted to go to Varanasi, on the Ganges River, which is a very holy place in India. There are many steps leading down to the river which I thought would be near impossible in a wheelchair but Enabled traveller had made a ramp for the steps so I managed to experience the sunrise rituals on the banks of this incredibly spiritual river. I wasn't able to do things like the boat trip that most tourists do along the river and there were some palaces for example where I wasn't able to visit as much as the able bodied tourist but I still feel it's worth going and experiencing what you can rather than missing out on everything.

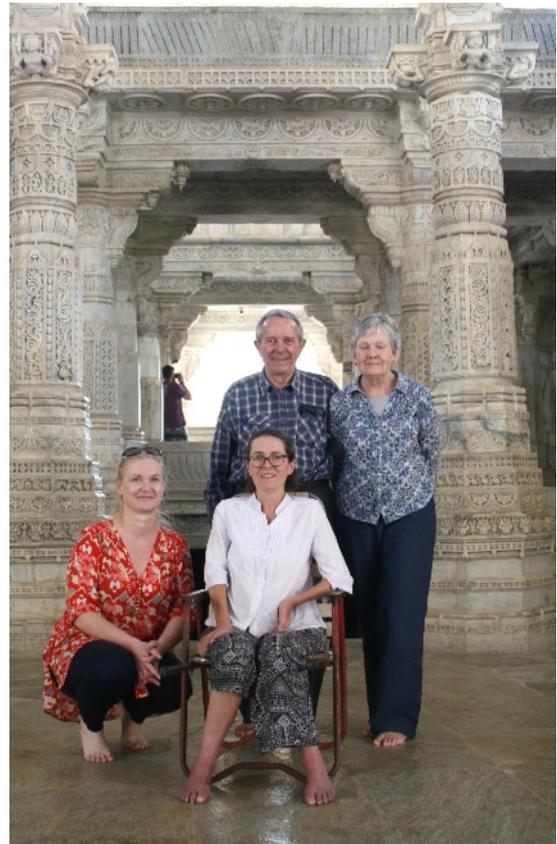
People went out of their way to help and my overall impression is that India is really trying and meeting the expectations of the disabled traveller.

* * * * *

More of Lisa's 'Holiday Snaps' . . .



These chaps could easily have been patients of Lisa's when she was working with International Animal Rescue!



With her parents and carer Janette at a Jain Temple. Note the locally-produced 'sedan chair'!



Up the steps at Varanasi (previously known as Benares)



For more on assisted travel in India, see <https://www.enabletravel.com/en-uk>

Travel with a Wheelchair

There are now many companies specialising in travel for people with reduced mobility. Along with the one which Lisa used so successfully in India, a couple of others are:

<http://www.accessibletravel.co.uk/>

and <https://pearlkingtravel.com/>

. . . and this site compares accessibility in London, Barcelona and New York:
<https://www.uksmobility.co.uk/blog/2018/01/disability-travel-accessibility/>

We would be very interested in hearing of your experiences of travel and accommodation when using a wheelchair. Please let us know how you got on, and whether you would recommend the firms you used. Eventually we should end up with a database of great practical use to members in the future.

Note: Lisa is again inviting all those living with MND and their family to join her at home on Wednesday 4th July for a special Drop-in support meeting cum Pool Party!

Her swimming pool, complete with hoist, will be available, so come along suitably equipped and hope for sunny weather!

Details on page 6

Coming up

July 'Drop-in' Support Meeting

On July 4th, our meeting will be hosted by Lisa Milella at her home. She kindly did this last summer, and those who came along agreed it made a very pleasant change from our normal venue in the Cathedral Refectory.

Lisa, who is living with MND, added a hoist to her pool equipment last year, so anyone with reduced mobility can have a dip if they feel like it. Be Prepared and come along with your cozzie!

Lisa's address is: 'Midsummer Cottage', 53 Parvis Road, Byfleet, KT14 7AA, and the door will be open from 2 pm.

Many thanks to Lisa and Marjorie for their kind hospitality!



Pot plants needed!

We'll have a stall at the Cranleigh Carnival on Saturday 30th June as usual, and need some stock to sell. Plants always do well, although other stallholders have the same idea.

Could you have a look around the garden to see if you can spare some, and if they're in pots with a label that would be fantastic. That way, even those of us on the stall who are horticultural ignoramuses can sound knowledgeable if customers ask what it is, how you look after it and so on.

Does anyone know a garden centre owner or manager who could let us have some plants for resale? Bring anything you can spare to any Committee member or bring it along on the day - thanks.



National AGM and Annual Conference

Saturday 14th July

The AGM of the national MND Association will again be held at the Radisson Blu Hotel, East Midlands Airport.

There is no charge for pwMND, carers and family members, and AVs. Others pay £15, which includes lunch.

For more info, and to register, go to the 'News & Events' section of the main MND website:

www.mndassociation.org

Street Collections

We've made a start on this year's programme, but there's still plenty of opportunity to help with separating the Great British Public from their change (and with luck, bigger coins and even folding money . . .)

Camberley, Godalming and Farnham are done, leaving:

16 June	Cranleigh
30 June	Haslemere
7 July	Guildford
11 Aug	Woking
18 Aug	Staines
8 Sept	Aldershot

We need volunteers to cover each town centre adequately, so if you can help with any of our collections, please let Mary know on 01483 419774, or email mary.carr2326@btinternet.com

We'll also have the rosters at the AGM for you to add your name . . . but don't let that put you off!



Station Collections

These are done entirely by the committee, as the railway companies have a limit on the number of collectors they'll allow in their stations at one time. However anyone wanting to try one for size is welcome to volunteer - no doubt a committee member would be happy to hand over and have a lie-in instead!

This year's programme is almost complete, with only Guildford still to do, on the 5th July.

8 March	Godalming
15 March	Aldershot
19 April	Weybridge
20 April	Woking
3 May	Haslemere
5 July	Guildford

Accessible Boating



The good ship 'Dawn'

Even if you have limited mobility, it is possible to enjoy a relaxing trip on the Basingstoke Canal!

The Accessible Boating Association (ABA) is a charity offering opportunities for disabled people or those with mobility difficulties to go boating on the Basingstoke Canal from Colt Hill Wharf, Odiham in Hampshire.

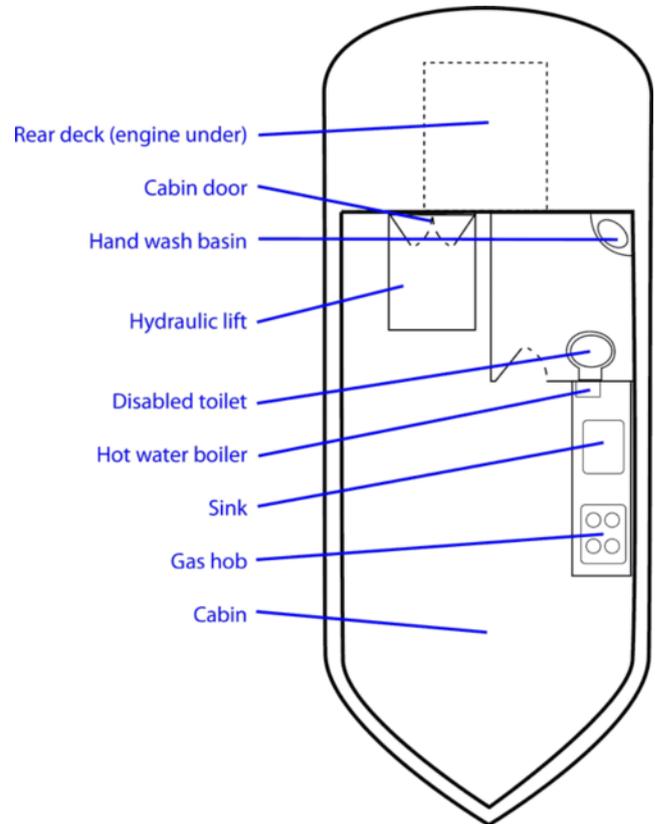
'Dawn' is equipped with a wheelchair lift, disabled toilet and clear floor space below to accommodate up to four wheelchairs.

The hire cost is £100 for four hours, but split between a group of passengers, it becomes quite reasonable. Normally, the ABA provides the crew of two, and the maximum passenger load is then 10, with a wheelchair counting as two. They also run scheduled 3-hour cruises for £15 including one carer/supporter. This year's schedule appears on the next page.

Cruises either head west to Odiham Castle (from which King John is supposed to have departed for Runnymede to sign Magna Carta in 1215), or east to Barley Mow Wharf.

If you'd like to sample this delightfully peaceful way of seeing bits of the countryside you can't normally reach, let us know and we'll try to get a group together to split the cost.

And 'The Waterwitch' is a nice old pub a few yards from the boarding point if you need to take on additional victuals for your voyage!



Dawn's layout below

A second, larger, boat called 'Madam Butterfly' is available for self-drive holiday hire.

Her equipment includes a hospital bed, accessible loo, lift and an optional hoist. She can accommodate up to 7 overnight, so a complete family could go along with someone living with MND, making possible a memorable short break.

For more information on all ABA activities, please see:

<http://www.accessibleboating.org.uk/index.html>

Accessible Boating Association

Registered Charity No 295034

SCHEDULED TRIPS ON DAWN IN 2018

These are the dates for scheduled trips on Dawn for 2018.

Depart: 1100 Return: 1400

Colt Hill to Odiham Castle or Colt Hill to Barley Mow Wharf

Cost: £15 per person with one carer/supporter free of charge.

Pre-booked trips only. Maximum group size four persons.

Passengers are welcome to bring a packed lunch on board.

email: bookings@accessibleboating.org.uk tel: 07934 926683

APRIL	THU	12	26
	SAT	14	28
MAY	WED	9	23
	SAT	12	26
JUNE	SAT	9	23
	TUE	12	xx
JULY	THU	12	26
	SAT	14	28
AUG	WED	8	22
	SAT	11	25
SEP	TUE	12	26
	SAT	15	29
OCT	TUE	2	16
	THU	11	25
	SAT	13	27
	WED	17	31

Financial Update:

from 27th February to 27th May 2018

Static Collecting Boxes

The collection boxes located in West Surrey's shops & taverns yielded a total £ 139.40

Select Convenience, Bramley:	£ 41.90
Fairlands Convenience Store:	£ 19.24
Ten Aker Farm Shop, Chobham:	£ 78.26

Donations/In Memory

Since our last Newsletter donations totalling £ 374.07 have been received.

Branch Fund Raising

This year Weybridge and Haslemere were added to early morning excursions to local railway stations armed with our collecting boxes. So far £ 561.38 has been donated during these visits; our final station will be Guildford on 5th July starting at 6.30am and finishing at 9.30am. The Street collections have also started with donations of £768.04 resulting from Camberley and Godalming. The weather was glorious on the May Day bank holiday when the Branch had a pitch at the Haslemere Charter Fair. A 'Guess the Length of Ribbon' competition plus miscellaneous sales yielded a net profit of £94.00 at this bi-annual event.

Other Activities

We are so very grateful to those individuals and groups who organise their own fund raising events to support the MND Association. Since the beginning of March a total of £ 3,162.05 has been raised on our behalf.

Roger Dyer continued with his sporting events generating £300.00, Jim Kemp's talk to a Probus Group raised £50.00, Jane Cockerham organised a lunch and raffle swelling our funds by £ 1,250.00 and Mary Hainline's annual Open Victorian Garden 3 day event resulted in £ 1,562.05 being deposited in the coffers. Many, many thanks to our Third Party Fund Raisers.

Care & Equipment

The Branch has received numerous to benefit people in our area in need of care, special services and equipment resulting in £ 8,387.34 being spent during this quarter.

Thumbs Up Club Winners

Our lucky winners were:

March :	E Williams	(231)	£ 50.00
	K Newnham	(180)	£ 30.00
	P Harwood	(275)	£ 25.00
	E Purchase	(021)	£ 20.00
April:	T Whitehead	(255)	£ 40.00
	A Hopwood	(078)	£ 30.00
	L Brewster	(054)	£ 25.00
	M Dean	(182)	£ 20.00
May:	S Aves	(176)	£ 40.00
	S Franklin	(226)	£ 30.00
	R Hodgson	(277)	£ 25.00
	C Jackson	(248)	£ 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

Annual Financial Report

As noted in the last newsletter, copies of the Annual Report were made available for the aborted AGM in March, and will re-appear for our next attempt this month. In addition, they were sent to members with the last newsletter as an attachment.

The Treasurer will report in greater detail at the postponed AGM on the 24th June, but the Branch finances are healthy and improving, in spite of a shortage of volunteers.

As noted last time, we are really grateful to the third party fundraisers who ably fill the gaps, and encourage every member to remember the Branch if they have any young family members or friends who are looking for a good cause to support in some exciting sponsored challenge!

Research latest

Research Information update

The national Association produces a range of Information Sheets on all aspects of MND research.

They are currently updating the format of these, to be consistent with other information sheets available across the Association, and to present information in a clearer and 'easier to read' format. At the same time they are checking the content to make sure the information presented is current and correct.

'Research we fund 2018' is the first new-style information sheet to 'go live' on the main website. In it they explain what type of research projects we fund and how they make the decision to fund them. They also list summaries of the 79 projects we are currently funding, or are committed to funding, in 2018.

Physical Exercise - Good or Bad?

According to the World Health Organisation (WHO), insufficient physical activity is one of the leading risk factors for global mortality and is on the rise in many countries. People who are insufficiently active have a 20-30% increased risk of death compared to people who are sufficiently active.

On the other hand, we hear anecdotal evidence of many sportsmen developing MND. A paper has been published about this, just as the MNDA have been preparing some information in response to the frequent questions about whether someone's MND was triggered by their sports activities. In summary, the authors of this paper believe they have shown a significant positive relationship between physical activity and likelihood of developing MND. Other previous studies suggested no direct link with the activity itself, but possibly environmental factors linked to the activity.

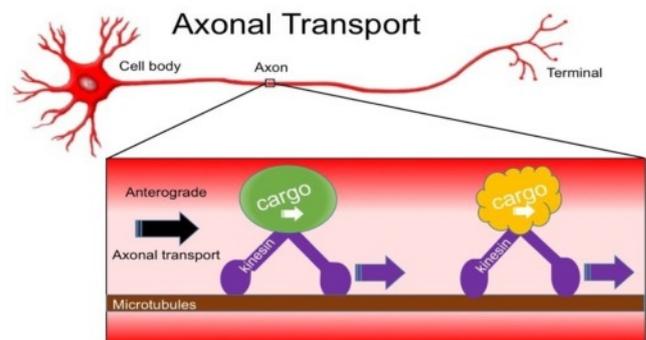
The MNDA review of the paper says "While this study adds to the cumulative evidence that physical activity is associated with MND, it is crucial to say that it is not a major factor in the development of the disease. Rather, it is another risk factor that together with others (including genetics) may increase the chances of MND development. It is likely that physical activity is only a risk factor in the presence of certain genetic profile, making some people more susceptible to motor system damage."

The first of three notes on this subject has now appeared on the MNDA research blog. The above is a very sketchy over-view, and you are encouraged to read the blog, with its links to relevant papers, for more information.

Another gene implicated in MND development Is discovered

The international nature of MND research has come up with its latest prize. The discovery of the KIF5A gene is the result of a very large collaboration of over 200 authors from MND research institutions from 5 different countries and 9 consortia across Europe, Australia and the US, that collaborated openly to combine their analytical skills and MND patient genome sequencing data to identify this MND/ALS gene. The consortia included the MND Association-supported Project MinE, an international collaboration aiming to analyse over 20,000 DNA samples.

KIF5A is a 'kinesin', whose job is to transport proteins from the cell body of a neurone to its terminal along the axon. In the case of the motor neurone from the spine to the foot, this may be 10000 times as long as it is wide! (1 metre long, about 0.1 mm wide). It's thought that if the kinesins stop working and the proteins are no longer brought to their destinations on time, the neurones may be damaged in such a way that MND results.



More FUS !

A mutation in the *C9ORF72* gene causes familial MND in around 35% cases and FTD in 25% of cases, by causing toxic accumulation of TDP-43 protein in the neurones. Another neurone-toxic protein is *FUS*, and this causes MND with FTD in 4% of familial, and 1% of sporadic cases.

A new paper from the Universities of Toronto and Cambridge finds that the protein Transportin1 and the methylation of arginine play a vital role in preventing aggregation of the protein in MND and FTD, so they can now start looking for a way of preventing this. Another piece of the jigsaw in place!

For more on any of these items, go to the MND Research Blog: <https://mndresearch.wordpress.com>

Can you help?

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

We could also do with a computer-savvy person who can help with our website and social media, and a writer familiar with desk-top publishing software and graphics to improve on Bob's amateur efforts in this newsletter and elsewhere!

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.

'Drop-in' Support Meetings

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, usually 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.

Please note: our July meeting will be at Lisa's home;

*'Midsummer Cottage'. 53 Parvis Road,
West Byfleet, Surrey KT14 7AA.*

Open Meetings

Summer Meeting and AGM

*Surrey Technology Centre
Sunday 24th June 2018
12.30 to 3.45 pm*

Guest Speaker:
Dr Brian Dickie
Director of Research Development

***Always check our website and Facebook
for up to date details***

How to find us

By car: 40 Occam Rd, Guildford, GU2 7YG

Up Gill Rd with the RSCH to your right, at the top, turn right at the roundabout into Occam Rd. The Tech Centre is first on your right.
Adequate free parking.

By train: 25 min walk from Guildford Station, or take No 5 Bus.

By bus: No 5 Bus to the RSCH (every 30 mins from Guildford Bus Stn), then follow the car instructions above.

Return on No 4 Bus from RSCH

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 Husaundee
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:

Branch Website:

www.mndawestsurrey.co.uk

Facebook:

www.facebook.com/MNDAWESTSURREY

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

National Office:

MND Connect 0808 802 6262

