

Our Branch's 25th Birthday Celebration

This June our branch celebrated its 25th birthday. Around forty members came and enjoyed gorgeous weather and lots of delicious cakes at The Ark in Turners Hill.

A beautiful birthday cake was specially made for the occasion and cut by Carol Rieley, Sue Sheppard (representing the longest serving members) and Sophie, the youngest member of our branch.



Incapacity benefit

The MND Association is working to ensure that people with MND are not subjected to wholly inappropriate new assessments

As part of the new Coalition Government's programme of reforms, it has announced that it will continue with the Labour Government's plans to migrate all current claimants of Incapacity Benefit (IB) to the new Employment Support Allowance.

In principle, this means that everyone who currently receives IB will be assessed for their fitness to work, although there are some exceptions to this. (Continued on page 4)

Diary

September 19th

Branch Meeting at The Ark in Turners Hill at 3pm

October 1st

'An Evening with Simon Brett' renowned author, at the Capitol Theatre, Horsham. Tickets £10

October 23rd

'The Fire Ball', Cisswood Hotel, Horsham. Black Tie event. Buffet, Entertainment, Dance.

Tickets £30 from 01403 750991

November 13th

Annual Quiz Night at St. Francis Social Club

December 5th

Branch Meeting at The Ark in Turners Hill at 3pm

FUNDRAISING

Circle of Life 2010

Liam Dwyer organised a fantastic event raising over **£2,000** for the branch. Friends and family motorcycled in all manner of fabulous machines, around the M25 to complete 'the circle of life'.

THANK YOU TO EVERYONE WHO TOOK PART!



Charlie Sheppard's Marathon Run

In our previous newsletter we were asking you to support Charlie with his upcoming marathon. We can now tell you that Charlie completed the course in an amazing 3 hours and 58 minutes and raised a fantastic **£1,661.75!!**

WELL DONE CHARLIE!!

Haywards Heath Town Day

On Saturday 11th September, members of the branch braved the wet and rain, roof collapse and runaway balloons to hold a stall at this annual event held in Victoria Park and raised approximately £140! They sold lots of delicious home made cakes, jams and chutneys, and held a 'Name the Doll' competition.

A lovely day was had by all, and thank you to all who helped and came along in support.

Hire A Hat For Charity!

Jenny Rimmer, formerly an Occupational Therapist working at the Princess Royal Hospital, decided to start a hat agency with all profits going to the Motor Neurone Disease Association. So if you are off to Royal Ascot, a wedding or just need a hat for that special occasion give Jenny a call on:

01825 723746

Lingfield Equine Vets sponsored a charity polo day on the 13th June 2010 at the Sussex Polo club and arranged for us to collect for the MND Association at the gate.

The weather was glorious, many came and enjoyed a lovely day out and we collected the marvellous total of **£790!**



MND Association
2010 Raffle



Tickets £1

MND Association 2010 Raffle

The first raffle last year raised almost £135,000 for care support services and research projects, almost £18,000 of which was raised solely by branches and groups. The closing date for entries this year is Wednesday 20th October with the winners being drawn on Friday 29th October.

Our branch needs voluntary donations, so we will be selling tickets at as many events as we can, and asking for everyone's support to sell them to family, friends and colleagues, and then **send all ticket stubs and funds directly back to our branch.**

For more information, please talk to a member of the committee, take a look at our website at <http://mnd-westsussexnorth.com> or contact the MND Association.

RESEARCH

A NEW genetic cause of MND suggests cellular 'traffic jams' may play a role in all forms of MND.

Researchers from Japan have recently announced that a rare mutation in a gene called 'Optineurin' (OPTN) can cause MND. They also suggest that OPTN may be involved in causing the disease for all forms of MND.

What does this mean for people affected by MND?

Mutations in the OPTN gene are extremely rare and have only been found in a handful of families in Japan. This discovery will however, help us to glean a deeper understanding of what causes all types of MND.

What did the researchers find?

The researchers studied the genetic spelling differences of 16 people with MND from close blood relative marriages, 76 people with the inherited form of MND, and 597 people with the randomly occurring sporadic form of the disease. From this they identified eight individuals with mutations in OPTN, seven of which were from close blood marriages and one was a sporadic case. To make sure that the gene mistakes were not a 'common' spelling error, they also checked their results against controls who did not have the disease. They could not find the spelling difference in any controls and therefore it is likely to be the cause of MND for these people.

By studying what goes wrong on a cellular level for people affected by the OPTN gene mistake, the researchers were also able to determine that MND may be triggered by a loss of function of OPTN, where it plays an important role in the trafficking of substances around the cell and indeed out of the cell. It also plays an important role in regulating cell death.

Further to this, the researchers also found that OPTN is faulty in both cells that are affected by SOD1 mistakes as well as TDP-43 mistakes (two previously identified genetic causes of MND). As the product of these gene mistakes is usually never found, OPTN may be a more general 'marker' for all types of MND.

More information

Please contact our research development team at research@mndassociation.org or on **01604 611880**.

PATRICK the incurable optimist



This year the MND Association will be highlighting the amazing and positive spirit of the MND Association community.

Artist and father of three, Patrick Joyce, has MND and has set himself a challenge to paint the portraits of 100 incurable optimists before he loses the ability to paint forever.

Patrick said: "I started this **100 portraits project** in the hope that I could show that behind the horrible statistics there are people fighting tooth and claw to stop this disease, people giving up their lives to care for the sufferers and people living with it, with dignity, fortitude and a sense of humour.



To find out more, please contact the MND Association or visit their homepage under Awareness Campaigns.

Picture shows Julia Franklin. Former Chairman of West Sussex South

Riluzole: An Update

The MND Association is continuing to work closely with the manufacturers of riluzole, Sanofi Aventis, to find a long-term solution riluzole shortages.

The shortages are not caused by problems with the manufacture rather, significant amounts are exported to other EU member states, where a higher price can be obtained. Although frowned-on by the Government and NHS, this practice is legal under EU trade laws.

Anyone who is having difficulty obtaining riluzole should ask their pharmacist to call:

0800 854430

To arrange for a supply to be couriered direct to them.

This service is set up to supply riluzole within 24 hours in most cases, and 48 hours maximum.

Committee Details

Chairman

Carol Rieley
01444 482387

Vice Chairman

Chris Sheridan
01444 245486

Secretary

Liz Carter
01444 232099

Treasurer

Alf Bodimeade
01444 482260

Newsletter

Editor

Natasha Newton
07812122932

Association

Visitors

Chris Sheridan
Robert Mynors
Linda Smillie
Jill Shuker

Disabled access information online

Look out for a website called **Disabled Go** that allows you to search for a whole range of accessible services. This includes hotel accommodation, restaurants, pubs, hospitals, etc. The listings have been surveyed, with photographs and detailed information about access, e.g. entrance, reception areas, toilets etc. Not only do they include photo evidence, but often dimensions of rooms and, in some cases, details about heights of beds, bathroom facilities etc.

It seems that website works in partnership with local authorities about access information and the database of access guides is forever growing.

This website has already been posted as a link on the MND Association main website, under Life with MND/getting more information/useful internet sites. You can also access the website at www.disabledgo.com/ or via the 'Useful links' on our website

Incapacity Benefit (Continued from Front Page)

The MND Association has written to the secretary of state for work and pensions, Iain Duncan Smith, to make it clear to him that people with MND who have left the workforce should not be assessed for a return to work, and they are working further with his officials to ensure that people with MND are not subjected to wholly inappropriate new assessments.

The migration process will begin in April next year and take three years to complete. People with MND who receive IB may receive letters next spring explaining what happens next – in most cases, this should simply be an automatic transfer to the new benefit.

The MND Association will be providing further advice nearer the time. In the meantime, we would be interested to hear the experiences of any person with MND who has been subjected to a Work Capability Assessment, either for IB or Employment Support Allowance.

The MND Association believe that it is wrong to subject people with MND to these tests. Evidence of what is happening in practice will assist them in making this clear to the Government, so please email any experiences to:

john.kell@mndassociation.org



Helpline: 08457 626262

Email: mndconnect@mndassociation.org

Website: www.mndassociation.org

Address: PO BOX 246, Northampton,
NN1 2PR

National Office:

David Niven House, 10-15 Notre Dame
Mews, Northampton, NN1 2BG

Telephone: 01604 250505

Branch Email:

westsussexnorth@mndassociation.org

Branch Website:

<http://mnd-westsussexnorth.com>

Treasurer List of Monies Received

Street Party	228.00	Darran Stone (Football Match)	868.62
City Quiz	2,660.00	Sharpthorne WI	1000.00
In Mem CS	55.00	Jill Shuker	25.00
In Mem IM	20.00	Tesco Gatwick Collection	582.16
Horsham Street Collection	1304.63	Haywards Heath Collection	752.78
Rev J Zubinden	50.00	Mrs S Jarvis Kitchen Party	110.00
Polo Match	790.31	Staplefield Village Lunches	150.00
In Mem AB	135.00	Mrs J E Madgwick	15.00
Darran Stone Sky Dive	3078.34	St Wilfrids Women's Fellowship	
Mrs Stone Collection	30.91		100.00
In Mem KG	1180.00	Staplefield Cricket Match	
Mr / Mrs Ashby	20.00	(per Ron and Gill Stevenson)	924.38
Friends of Ron Stevenson		Horsham Fabric Shop	26.67
(Art Gallery)	100.00	HH Town Day	138.20