

### HAPPY NEW YEAR!!

#### ART EXHIBITION

A very exciting fundraising event will be coming up in March..

If you have a flair for art or know someone who does, please come along to the Art Exhibition at Staplefield Village hall. We are looking for people to submit paintings, drawings, sculptures and photographs during January, which can be exhibited.

To enter contact Rachel or Ian on 01293 562358 before January 28th or submit your images (not more than 2) to [Rachel@gingermoo.com](mailto:Rachel@gingermoo.com)

#### Diary of Events

##### **Meetings at 3pm at The Ark, Turners Hill**

20th March	25th September
26th June	4th December

##### **Other Events:**

19th March	Art Exhibition at Staplefield Village Hall
6th April	AGM at Haywards Heath Age UK Centre
17th + 18th June	Street Collection at Burgess Hill
25th June	Street Collection at Horsham

#### January Meeting



Around thirty members, including seven people living with MND, attended our re-scheduled afternoon meeting on Jan 16th. Helen Arnold, a local harpist, entertained us with her beautiful music.

Dr Steve Dyer (pictured) was introduced as our newly appointed president.

Rachel Cowley, owner of the Ginger Moo Gallery, came to tell us more about the Art Exhibition and to encourage as many people as possible to show their talents.

#### ‘An Evening with Simon Brett’



On October 1st Simon Brett, the author and playwright, performed his one man show ‘A Crime in Rhyme’ in the studio at the Capitol Theatre in Horsham.

As part of his introduction he said how pleasant it was to be in a room full of people instead of the state of isolation which is normal for a writer.

A smaller than hoped for audience thoroughly enjoyed his clever and amusing use, and occasional abuse, of language.

This was followed by a lively question and answer session about his life and work.

An excellent raffle and Simon’s kind donation of several of his books swelled the total made to £547

# Fundraising

## Fireman's Calendar



In addition to organising the 'Fire Ball', the Gatwick Firemen have produced a charity calendar showing themselves in action. Over £4000 has been raised so far.

The Fireball at Cisswood House raised an absolutely wonderful £3,580

**Well done and THANK YOU to all!**

## Branch Annual Quiz Night

The annual quiz night was held on Saturday 13<sup>th</sup> November at the St. Francis Social Club. A total of 93 people made up 17 teams to answer questions set by the branch's treasurer, Alf Bodimeade, who also acted as Quizmaster.

The quiz ended with a tie-break between four teams which was won by the team from Cuckfield, led by Chris Openshaw. Embarrassment for the branch chairman, Carol Rieley, was avoided this year as her team, which had won two out of the previous three quizzes, only managed to finish fifth, one diplomatic point behind those tied for first place. The event raised a most gratifying £979, which will be used to help local people living with Motor Neurone Disease.



## Royal Parks Half Marathon

Ron Stevenson, second from right with daughter Polly and wife Gill holding the banner, wrote this about Polly's entry:

Apart from Polly, the rest of the team was Jo, Francis, Rich, Carl, Nicky and Tom. They all finished and raised money for MNDA. Polly has exceeded her target amount of £1,500, and has presently raised over £2,400 and still climbing.

Three miles in, poor Polly's injured knee broke down so the last 10 miles was completed in some considerable pain and rendered her target time of two hours unreachable. However, 2 hrs 21 minutes was still respectable for a first attempt and she was the fastest of her team.

Great feelings of accomplishment engulfed all at the finish – a special sense of camaraderie between the members of the team was evident. A superb day, a wonderful occasion and everyone and their charities were winners!!



On 16th September, the Cuckfield Ladies Club presented our branch with a cheque for a fantastic £1,700!

It was accepted by our chairman, Carol Rieley, who expressed her thanks for raising such a splendid amount.

# Research

## **New Gene Identified as Cause of Inherited MND**

The third gene to be identified in 2010 as a cause of the inherited (familial) form of MND, has been done by US and Italian researchers led by Dr. Bryan Traynor.

Dr. Traynor and colleagues have identified how members of an Italian family affected by familial MND all have a mutation in the genetic instructions for making a protein called Valosin-Containing Protein (VCP). These results were later verified in a larger group patients, suggesting it may account for approximately 1 to 2% of cases of familial MND.

VCP plays a regulatory role in 'marking' unwanted proteins for destruction or recycling. If this function is disrupted, then a build-up of 'marked' proteins occurs because they are not being destroyed or recycled, which is seen in patients with MND.

Dr. Brian Dickie, director of research development at the MND Association, said "This new gene discovery is an important advance because it confirms that there is a link between the VCP gene function and the build-up of proteins as an underlying cause of the degeneration of motor neurones."

Please contact MND Connect on 08457 626262 or at [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org) for any further information.

## Researchers Confirm Disease Causing Gene

A study led by MND Association-funded researchers has confirmed that rare mutations in a gene called VAPB can directly cause the inherited form of MND.

In 2004, researchers identified VAPB as the disease-causing gene in a small number of Brazilian families affected by inherited MND. However, scientists have been unable to find problems with VAPB in MND-affected populations outside of Brazil until now.

### What does the VAPB do?

Many types of cells, including neurones, contain 'production lines' where substances produced by the cell are assembled, sorted and sent on to their appropriate destinations. Under normal circumstances, VAPB helps the cell to respond if this production line starts to get overwhelmed and backed up. The researchers established that when VAPB is faulty, it accumulates in clumps - similar to those seen in other types of MND, ultimately contributing to the neurones death.

This study discovered a British person with familial MND with a VAPB mutation. The mutation was in a different position within the VAPB gene than the Brazilian families, but they demonstrated how both faults can cause degeneration of motor neurons.

Researchers hope that discovering the genetic causes of the rarer familial MND will help improve the understanding of sporadic MND, and lead to the cure.

## **Mice with ALS experienced a delay in motor-related symptoms when fed a Spirulina diet**

Researchers at the University of South Florida have found that Blue-Green algae (also known as Spirulina) may be capable of delaying the onset of Amyotrophic lateral sclerosis (ALS), a form of MND. Researchers at the University of South Florida, believe that Spirulina may have combined anti-inflammatory and antioxidant characteristics that support motor neurons, helping to offset the symptoms of ALS. The study shows that feeding a G93A mouse model a nutritional Spirulina diet over a 10-week period resulted in delayed disease progression and motor problems, decreased motor neurone death and the reduction of inflammatory markers.

"The focus of our future ALS experiments will include motor neurone counts and examination of lifespan following dietary Spirulina supplementation in symptomatic ALS mice," said Bickford.

For further information, please go to:

<http://www.dailytech.com/ALS+in+Mice+May+be+Treated+with+BlueGreen+Algae+Supplement+/article20455.htm>

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## Documentary Featuring MND Wins Award

A documentary called *'Into That Good Night'* directed by Chris Eley, featuring a man living with MND, has won an award at the annual Ability Media International Awards.

It was first shown on channel 4 in 2009, following three terminally ill people as they take part in a photography project run by St. Christopher's Hospice, London. The project aimed to create portraits and provide a rare insight, the individuals talked about who they are and share their fears about illness and mortality.

Henry Marcuzzi, a well respected lighting cameraman, was featured, this time in front of the lens, raising awareness of his personal experiences of MND. Henry was diagnosed over three years prior to the filming, and was very keen to be involved.

Henry said: "At times since my diagnosis I have felt very alone. This documentary gave me the opportunity to see others who are in a similar position. Taking part was a way for me to externalize the hatred and venom I feel towards MND."

"Since my diagnosis I have felt the need to raise awareness of this horrible disease. This has provided me with a very effective way to do so. It is ironic that I may have more influence on people now than when I was healthy and fit."

"I used to think I could beat the disease, now I know I can't. However, I try not to dwell on that. I have to just live for the moment. I see MND as the second part of my journey. I had one life before diagnosis and now I have another one."

For further information, please contact Mel Barry, Communications Manager on 01604 611887, or email on [mel.barry@mndassociation.org](mailto:mel.barry@mndassociation.org)



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### Treasurers List of Monies Received

Mrs. Stone	£35
Cuckfield Ladies Club	£1,700
Staplefield Cricket Ron and Gill Stevens)	£476
City Quiz (additional)	£1,110
Simon Brett Evening	£547
Eileen McLeod	£150
Robin Hughes	£500
Gift Aid Reclaim	£860
Waitrose	£470
Haywards Heath Quiz Night	£974
Darren Stone Ball	£3,550
SC Tribute Fund	£19
Pam Taylor	£25
Peter Robson	£25
Raffle Profit at Staplefield Village Lunches	£100
P Reynolds (Sale of JR Calendar)	£10
R Smillie	£100
H E Grace	£20
Eve's Tea Room (late night shopping)	£44