

### **Diary of Events**

**Haywards Heath Street Collection** 10th September  
**Meetings at the ARK, Turners Hill** - 25th September, 4th December  
**Annual Quiz** November 19th

## **June Meeting**

### **Floral Heart**

Following the success of the original Floral Heart it was decided to run the event again at our June meeting. After the meeting it was left in the grounds of Turners Hill church



### **Nick and Hannah**



Membership secretary and former committee member Nick Cottom married Hannah Massey at the Church of the Presentation in Haywards Heath on the 9th July.

At the June meeting they were presented with a beautiful rose and ceramic plant pot. Everyone gave them best wishes for their future happiness.

## **Quiz Night November 19th**

The venue will be, as usual, the St Francis Social Club at the Princess Royal Hospital.

Teams will consist of up to 6 persons and tickets will be £10 per person.

A hot supper will be provided and the bar will be open.

If you have not been before why not get a team together and join us, you will find it's great fun and why it's so popular.

Tickets can be obtained from Carol Rieley on 01444 482387 or email [mnd@rieleyjc.plus.com](mailto:mnd@rieleyjc.plus.com)

## Wanted - a Treasurer

Earlier this year the committee was given some devastating news. Alf Bodimeade, our treasurer and top fundraiser with his 'City Quiz', let it be known that he and his wife, Jenny, had decided to leave the area and had put their house on the market. The sale has now gone through and they are now living in Horsted Keynes whilst they look for another property 'somewhere to the West'. This means that the branch has an urgent need for a new treasurer so if you would like to step in or know of someone who could fill the post please let us know.

## Natasha Newton



Natasha, our newsletter editor, has had to give up her position as the working hours in her new job frequently clashed with branch events and she felt that she could not find the time to do the job properly.

We are sorry to lose her and would like to thank her for her efforts.

Carol Rieley's husband, John, has stepped in to do the job on a temporary basis but it now means that we are also looking for a new editor. Please let us know if you can help.



Stephanie Barfield has just become an Association Visitor. She wrote this about her training.

*'I have recently completed MND Association Visitor training which consisted of two one-day sessions and a two-day residential, all of which were held at a very pleasant hotel venue in London, near to Euston Station.*

*Although I was already certain that I wanted to undertake the role of an Association Visitor, the training, which I found to be highly professional and relevant, served to convince me still further that I had made the right decision. The group in which I found myself consisted of a dozen would-be Visitors, of all age groups, from all areas of the United Kingdom, and each one with very different reasons for being there. There were those wishing to add a new dimension to their working lives, those who had personal experience of a loved one living with MND and retired folk like me who still wish to be actively involved in some area of life. By the time we had completed the course we had become friends and I know that we will continue to support each other as we start our respective journeys as Visitors.*

*Our training consisted of talks from Association officers and health care professionals, who gave us information on practical matters and the opportunity to make ourselves aware of, and in some cases handle, the various items of practical assistance which can be provided. We heard at first hand the views and experiences of a current Visitor and those of the wife of a gentleman who had recently died from MND. We took part in activities which in their turn served to highlight the practical and emotional matters that we are likely to encounter in our roles as Visitors, and challenged us to think about ourselves and the skills which we will need to develop. Everything that we did formed an excellent basis for what will become, we all hoped, a 'knowledge bank' in the future.*

*Throughout the course we were made very aware of the enormous amount of support and information which the Association provides and which we can tap into as Association Visitors, both for people living with MND (plwMND) and for ourselves. We also came away knowing that should we – either immediately or in the future – decide that this role was not for us it was perfectly all right for us to say so and that there would be no hard feelings if we made that decision. I feel that this is an essential thing to know when setting out on such an important journey as this; it illustrates the Association's commitment both to providing plwMND with the best possible support and assistance and to the well-being of their volunteers.*

*I would thoroughly recommend the Association's training to anyone considering becoming a Visitor; it's interesting, informative, challenging – and fun! It has been a very positive experience.'*

## **Researchers discover common cause of all forms of MND**

American researchers have uncovered what could be a pivotal disease mechanism in all forms of motor neurone disease (MND).

The team, led by Prof Teepu Siddique at Northwestern University Feinberg School of Medicine in Chicago, describes in the prestigious journal Nature how problems with the 'rubbish recycling' system in motor neurones appear to be integral to the degeneration seen in MND.

Prof Siddique's team initially discovered that mutations (mistakes) in a gene called UBQLN2 were the direct cause of the rare, inherited form of MND in a small number of affected families. UBQLN2 contains the instructions for making a protein called ubiquilin 2, which is part of a team that helps to recycle unwanted or faulty proteins in cells.

When the researchers went on to examine post-mortem samples of spinal cord and brain tissue from people with sporadic (non-inherited) MND and other types of the inherited form of the disease not caused by UBQLN2 mutations, in every single case they found ubiquilin 2 caught up in the tangled protein 'clumps' that are the hallmark of diseased neurones. This indicates that even when the UBQLN2 gene is not faulty, ubiquilin 2 still contributes to the disease process.

Although this finding comes hot on the heels of other important breakthroughs in recent years, this is the first time that scientists have seen evidence of a dysfunctional process common to all types of the disease, suggesting that it could provide an important target for future drug development. These results will now need to be verified by other research teams.

Dr Belinda Cupid, Head of Research Development at the Motor Neurone Disease Association, said: "This is a big news story for motor neurone disease research. The discovery of mutations in the UBQLN2 gene in families with the rare, inherited form of motor neurone disease has unlocked the significance of this damaged protein in all forms of the disease.

"We've known for some time that the waste and recycling system in motor neurones is damaged, but this is the first time that there has been direct proof. This discovery provides researchers with an exciting new avenue to explore as they search for an effective treatment."

## **Zebrafish - What have they got to do with me (and MND)?**

Zebrafish are increasingly becoming the organism of choice to study both early development and disease. But why are zebrafish important to MND research and can we really learn anything from a fish?

Amazingly, we share many of our genes with our finned-friend the zebrafish which means that we really can compare what happens in zebrafish with what happens in humans.

With transparent embryos, zebrafish offer a unique view into the developing fish which means that researchers can study their neurones under a microscope – a feat that is not possible in humans or other mammals. We can also learn about how the disease progresses in fish by measuring their muscle strength by the amount they move, and by measuring their progress swimming against a current in a tube.

Unlike us, zebrafish are also able to regenerate motor neurones if they become damaged. Interestingly – it is not that we do not have this capacity; we have extra signals that tell our motor neurones not to regenerate.

Zebrafish can therefore be used in MND research to gain a greater understanding of the processes that govern both the degeneration and regeneration of motor neurones to develop new and better treatments.

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**Lindfield Life**

In order to publicise the work of the branch Carol Rieley, our chairman, has been featured in the September issue of 'Lindfield Life'

The article was written by Emma Tingley, who, as a trainee Speech and Language Therapist, first met a patient with Motor Neurone Disease when working with Carol at the Princess Royal Hospital in Haywards Heath. It describes how Carol decided to become a Speech Therapist, her first experience of treating a person with MND, her decision to become Chairman when the branch was in danger of closing, the work of the branch and in particular the need for more Association Visitors.

Lindfield Life is available from the Post Office and shops in Lindfield.



The Association is asking people living with MND and carers to post a note or upload a picture to a facebook page, and explain why the chosen activity brings happiness.

The views expressed will help shape plans as the Association strives to enable everyone with MND to achieve the highest quality of life possible.

The Facebook page can be accessed at:-

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

Unfortunately our treasurer has been taken ill and has been unable to provide a list of monies received. Here are some of the major items. We apologise if your contribution is not listed here.

**Treasurers List of Monies Received**

The football match organised by the friends of Darren Stone has raised £2,405 so far

Sam Hopkins half marathon run has raised £2,457

The collection at Tesco, Burgess Hill raised £579.58

The Horsham street collection raised £1073.47

Sue Sheppard persuaded her company, SAS Global, to make the Motor Neurone Disease Association one of their charities of the year and we were given £12874.45

This has been ringfenced for a special project - more news about that later