

# HAPPY NEW YEAR!

### Carole Lloyd Receives Long Standing Service Award

In 2009 Carole retired as one of our valued Association Visitors. She was one of the earliest members of the branch, which will be celebrating its 25th birthday this year. Carole was given a rose on our Walk to D'feet in July and then, at our December meeting, was presented with her long standing certificate for the 11 years as an AV. She was thanked for all her hard work and dedication. This is her story...

*My first connection with Motor Neurone Branch was in 1987 when my husband was diagnosed. I used to attend the Branch meetings and found great comfort being with people who understood my problems as a carer and the situation of my husband. Maureen Stokes used to visit me to check if there was anything the Branch could help me with. I offered to be the co-ordinator for selling MND Christmas cards and have been doing this up to the present time. After my husband died in 1992 I had a year away from the Branch but got involved again. I felt with my experience I could help other carers and patients and in 1998, became an official Motor Neurone Visitor.*

*Over these years I have seen tremendous strides in the care, equipment provided and help given to The Professionals dealing with this disease. I have met some very brave people and have found it very rewarding and hope it is not too long before a cure is found.*



### Diary Dates

Branch meetings for 2010 at The Ark in Turners Hill are:

- 21st March
- 27th June
- 19th September
- 5th December

**5th June:** Horsham Street Collection including Pirie's Place and Swan Walk

**25th July:** Circle of Life - Motor cycle ride round M25!

**9th October:** Quiz night at St. Francis Social Club

### Securing the supply of Rilutek (also known as Riluzole)

At the moment, Rilutek is the only drug proven to slow the progression of MND therefore, when in spring 2009 some people were finding it increasingly difficult to obtain it, this became an immediate priority for the MND Association.

Following a meeting on August 20<sup>th</sup> 2009, the manufactures of Rilutek have instituted a **Direct Pharmacy Emergency Delivery** system. This means that anyone having problems obtaining their Rilutek through their pharmacy, can ask their pharmacists to call **0800 854430** to arrange for a supply to be couriered direct to them.



## Jo Brown Receives Extra Mile Award



Occupational Therapist Josephine Brown has proved she goes the extra mile in her job by winning a national award. Josephine, who works for West Sussex County Council Adults' Services, and is based in Crawley, was presented with the Extra Mile Award on Wednesday November 25th at St. Catherine's Hospice.

The award was given by the Motor Neurone Disease Association and recognised the support and care Health and Social Care professionals provide to people with the disease. Josephine was nominated by Kate Pottinger, Regional MND care development advisor. Peter Catchpole, County Council Cabinet Member for Adults' Services, said: "Our Occupational Therapists do a fantastic job helping people with physical impairments to live more independently. They focus on making the most of people's abilities and working closely with clients and carers to make their lives better."

*Photo of Jo Brown and Kim Illiffe*

Henry Smith, County Council Leader, said: "Congratulations to Josephine, it's always fantastic for our staff to get recognised for their hard work." Josephine has been working as an Occupational Therapist since 2006 and works with adults and children. Previously, she worked on an Acute Neurological Ward at Epsom Hospital. She said: "I am very pleased to receive the award, and really enjoy being an Occupational Therapist. I have a very supportive team who help me to go the extra mile for my customers and their carers. I feel the MND Association does great work, especially the volunteers who provide exceptional support."

### **Chance to Sign Up for 999 Text Trial**

*People with speech or hearing difficulties could help pilot a national emergency SMS (text messaging) service. To register, please go online at*

[www.emergencysms.org.uk](http://www.emergencysms.org.uk)  
or text the word 'register' to 999.

### **National Raffle Success**

The MND Associations first national raffle was a fantastic success! So far it has raised more than **£120,000!!!**

Douglas Graham, the director of fundraising said **"...once again, our members, supporters and volunteers have demonstrated their commitment to fighting MND and surpassed our expectations."** Following the success of this years raffle, plans for 2010 are underway!



### **Fund Raising**

**Lawrence Kingsnorth**, a friend of Marc Robson and member of Haywards Heath golf club, successfully completed the **Three Peaks Challenge** in May 2009, raising a colossal **£5,125** for the MND Association. **THANK YOU LAWRENCE!**



**Hannah Cousins** Granddaughter of Shirley and the late Geoff Crowther nominated MND as her form charity in year 7 at Millais school in Horsham.



During the school year Hannah and her friends raised a **fantastic** £118.81 through fund raising events including: guess the name of the teddy bear, how many sweets in the jar? They also sold drinks at sports day and provided a cake sale for the school staff.

**WELL DONE HANNAH!**

### **Ceiling hoist club**

The Ceiling Hoist Users Club (CHuC) has been set up by Equal Ability CIC to promote the interests of those disabled people who need hoists. To find out more about this group, please visit [www.chuc.org.uk](http://www.chuc.org.uk)

## Research

### 'Survival' Gene Found

**A gene that significantly influences the survival of people living with MND by 14 months has been identified by scientists in an international research collaboration, funded in part by the MND Association.** The international research team looked at 300,000 genetic variants in 2359 people with MND and 2814 unaffected volunteers from six different countries.

The results showed that they had managed to identify a 'protective' gene that extends the life of people diagnosed with MND – the first in the history of MND research. Researchers identified a genetic variation in the **KIFAP3 gene** and showed that people with two beneficial variants of KIFAP3 lived on average, nearly fifty percent longer than those who did not.

This research has implications for the design of MND clinical trials as it is possible that an excess of people carrying the beneficial survival gene variants in one group in a clinical trial might make it look as if a drug is effective when it is not, or vice versa.

If you have any questions, please contact the MND Association research development team on 01604 611 880 or by email at [research@mndassociation.org](mailto:research@mndassociation.org).



### New Research Initiative

**A major new £4.6 million research initiative involving leading MND researchers has been announced by the Wellcome Trust and the Medical Research Council (MRC).**

Professor Chris Shaw of Kings College, London, is leading an international group of researchers to investigate the suspected similarities between MND and a form of dementia called fronto-temporal dementia (FTD). They aim to develop disease models which mimic key features of MND and FTD to help them understand the biochemical events that initiate the degeneration of nerve cells.

Dr. Brian Dickie, the MND Association's director of research development, said "this research could make major inroads into understanding MND".

To find out more about up to date information on the latest findings relating to MND, please look on the MND Association website at the bottom of the research index page at [www.mndassociation.org/research](http://www.mndassociation.org/research), or request a hard copy from MND Connect on 08457 626262 or [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org).



### Helping Children Understand MND

In collaboration with Trinity Hospice, the Motor Neurone Disease Association has produced an interactive workbook developed to inform children aged between four and ten years old about MND.

The workbook entitled **When someone close has MND**, has been designed for adults and children to work through together as and when the time is appropriate.

Using well established coping strategies the workbook enables children to learn about MND

through taking part in a variety of activities. By using the workbook adults can create opportunities for children to ask questions and reflect on what is happening to them and their family.

Lucy Hawking, daughter of renowned physicist Professor Stephen Hawking knows what it is like to grow up with a parent diagnosed with MND. Talking about the new workbook Lucy said: "It recognises the complex emotions that are so overwhelming for young people faced with a loved one and MND.

Copies of **When someone close has MND** are available from MND Connect on 08457 626262.

Or contact Mel Barry, Communications manager, on 01604 611887 or 07760 765143. Alternatively, email Mel at [mel.barry@mndassociation.org](mailto:mel.barry@mndassociation.org).

### Carer's Rights

Crossroads care is the new name given to the charity Crossroads. It works with over 35,000 people and families, helping carers make a life of their own outside caring.

For more information please visit: [www.crossroads.org.uk](http://www.crossroads.org.uk)

### For your information

*The MND Association is changing the name of the Breathing Space Kit, to the **MND Just in Case Kit (JIC)**.*

*If you have any questions regarding this, please contact MND Connect on 01604 611870 or email*

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

## Committee Details

### Chairman

Carol Rieley  
01444 482387

### Vice Chairman

Chris Sheridan  
01444 245486

### Secretary

Liz Carter  
01444 232099

### Treasurer

Alf Bodimeade  
01444 482260

### Membership

#### Secretary

Nick Cottom  
01444 453508

### Newsletter Editor

Natasha Newton  
07812122932

### Association Visitors

Chris Sheridan  
Robert Mynors  
Linda Smillie  
Jill Shuker

## Mark Todd is new chair-elect of MND Association

At the 24<sup>th</sup> Annual General Meeting on 12 September, Mark Todd MP was voted Chairperson-elect of the MND Association.

Mark Todd is a founder member of the All-Party Parliamentary Group on MND and has served as chair throughout its nine year history. Most recently, the group was extremely influential in persuading the Government and NICE to progress work on making non-invasive ventilation more accessible to people with MND.

Mark says "I am proud to serve as chair-elect of the Association and then, I hope, chair of the Board of Trustees of the MND Association".

## Carers' Study

Kings College London has been commissioned by the Department of Health to carry out a study across the UK.

The study aims to find out whether people who care for adults aged between 18-65 years old with a long term neurological condition, can get the respite care they need. They're also wanting to find out about carers' past experiences of respite and people's opinions on what a 'five star' service would be like.

They are carrying out a nationwide survey which is available by post or online.

For more details on this, please contact the main researcher:

Dr. David Williams on 020 7848 5418  
or email [kclcare-study@kcl.ac.uk](mailto:kclcare-study@kcl.ac.uk)

## Get your MP to sign Parliamentary motion on MND

Mark Todd MP has tabled a motion in parliament called the Early Day Motion (EDM) calling for the Government to produce a national strategy on MND. This would set standards for the coordinated, holistic care of people with MND in order to improve quality of life and promote dignity in death.

The MND Association is encouraging as many MPs as possible to sign the EDM and asking anyone affected by MND to write to their MPs requesting that they sign too.

A list of MPs who have signed up can be found on the MND Association website: [www.mndassociation.org](http://www.mndassociation.org). If your MP isn't on there - drop them a line!! A template letter is available on the website, or you can contact Alison Railton email: [Alison.railton@mndassociation.org](mailto:Alison.railton@mndassociation.org) or call 01604 611842 for a copy.



**Helpline: 08457 626262**

**Email: [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)**

**Website: [www.mndassociation.org](http://www.mndassociation.org)**

**Address: PO BOX 246,  
Northampton, NN1 2PR**

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House, 10-15 Notre Dame Mews,  
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**Telephone: 01604 250505**

## List of Treasurers Monies Received

Floral Tribute 'In Memoriam'	£95	Maureen Stokes	£20
Walk to D'Feet	£210	In Memoriam JJ	£200
Tesco Collection—Burgess Hill	£645	Pam Taylor	£20
Shirley Crowther	£25	Hilltop WI	£33
Hanna Cousins Collection	£22	Marc Robson Walk	£25
In Memoriam DT	£143		
Haywards Heath Quiz	£912		
Sue Charman Tribute Fund	£20		
In Memoriam JC	£250		
Mr. Lejeune donations re. DC	£200		
Sainsburys Collection	£707		
Mitsui Sumitomo—Sailing day	£325		
Mrs K Bennett - donations in lieu of birthday presents	£40		
Mr & Mrs Thompson - donations at anniversary	£200		
Woods Family Fundraising - East Grinstead	£1,275		
Tim and Stevie Roberts Bridge Drive	£1,026		
Waitrose Horsham - Charity of the month	£597		