

## Christmas carol ding-dong



Happy New Year to all our readers. For events and dates see page 2.

THE 'BELLS OF HAMMERWOOD' rang out at the Ark on December 14th 2011, eight very seasonally clad lady campanologists, helping Christmas festivities on their way by playing familiar carols.

It was a great way to sing our way towards the 25<sup>th</sup> of December celebration. All were thanked by our branch Chair, Carol Rieley and each of the bell-ringers received a rose given by two of the youngest members of the branch.

Besides the entertainment there was the usual delicious cakes, tea and much conversation, as well as a 'bring -n-buy' sale, which raised just over £100.

Carol took the opportunity to thank Alf Bodimeade who, as many of you know, has now retired as our Treasurer, as he is moving away following a period in hospital. He was thanked for all his tireless work for the branch and was presented with a book token (picture page 4).

### Chair Slam Dunk's

**Quiz** SATURDAY 18<sup>TH</sup> November 2011, the West Sussex North branch of the MND Association held its now well established annual Quiz Night at the St Francis Social Club at the Princess Royal Hospital. It raised a magnificent £1000 to help people in the local area living with MND.

In total 99 competitors entered making-up 18 teams. The result was a bit of an embarrassment for the event's organiser, Carol Rieley. Not only was her team one of three tied for first place, she slam dunked (made a decisive score of) the answer to the tiebreak question.



Carol, presented with flowers at Quiz night.

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# Events

**4<sup>TH</sup> MARCH & 24<sup>TH</sup> JUNE 2012.**  
**3-5 pm**, branch social meeting. Anyone involved with, or living with, MND, come along for tea and a chat. Branch area covers Crawley, Horsham, East Grinstead, Haywards Heath, Burgess Hill, Hassocks, Venue: The Ark, Mount Lane, Turners Hill, West Sussex, RH10 4RA.

**24<sup>TH</sup> APRIL 2012. 8 pm**, branch AGM. AGE UK Centre, nr. Clair Hall, Perrymount Road, Haywards Heath. Full details will be sent to members and put on the branch website. Agenda to include: Election of committee members, review of last year's activities, plans for activities next year, a key note speaker.

**STREET COLLECTIONS:** Contact Carol Rieley if you want to come along and help.  
**30<sup>TH</sup> & 31<sup>ST</sup> MARCH 2012**, Horley, Gatwick Tesco.  
**9<sup>TH</sup> JUNE**, Sainsbury's Haywards Heath.  
**16<sup>TH</sup> JUNE**, Horsham town centre.

## With a Little help from my friends.

FEATURE STORY: Norman Hodson writes about living with MND and help given by our branch

MND is a complex disease with symptoms unique to each person, in some it can progress quickly, in fact I've known people last only a couple of years and for them things need to be arranged in haste. In my case, thankfully, development of the disease has been much slower.

I have been living with MND for 15-years now. Even so, adaptations need to be made swiftly to be of use. When the stairs in my old home were more than I could manage I moved into a bungalow which then needed ramps, a wet room had to be constructed and the carpets had to be replaced with hard flooring.

Next I was told I needed an electric-chair, but was also told that in practice this meant being added to a list and it was likely to be another 3-years before it could be supplied by the NHS.

So I needed to purchase one myself. Thanks to the tremendous work that the volunteers at the MND Association and the collections they make, a sum was donated towards the purchase of a new motorised wheelchair, for which I am very grateful.

At first I didn't think I would use the chair much, as I was happy on my crutches. However, after I had fallen several times I finally heeded the advice of Gill, my MND nurse. "Don't be too proud to use a chair to save your energy," she said, but at the same time when it came to the crutches the advice was, "use it, or lose it" i.e. keep using the crutches during the day to keep mobility and balance.

The West Sussex North branch of the Association arranges monthly visits by Linda Smillie, my MND visitor, who cheers me up. We have a good laugh

together, rarely talking about the gloomy aspects of MND, which is the way I want it. I'd rather be optimistic and enjoy life with my family.

Being a bit of a restless person and bought up with a certain work ethic I like to keep myself occupied. I often go to the gym and also volunteer at the Prince's Royal Hospital as well as working a helpline for disabled people in Brighton. All these things help to keep the brain ticking over.

Thanks to the Mobility car scheme I have a car with a rear hoist capable of lifting my Motability scooter. My next project is to adapt my new chair so it too can be hoisted aboard and used at the office, or anywhere else outside the home. A company in Bolney will fit the lugs and then, hopefully, next time you see me I'll be in the chair your readers helped pay for.

### Chair Slam Dunk's Quiz

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After prizes were awarded Ron Stevenson, a popular Staplefield resident who has MND, spoke warmly of the support he has received from the MND Association and expressed his thanks to Carol Rieley for all her efforts as chair of our local branch.

The West Sussex North branch would like to thank the staff of the St Francis Social Club, Adrian Carter, the quiz-master and to all those who donated raffle prizes, which included Ockenden Manor, Limes Restaurant and the Selsey Shellfish Company.

Norman Hodson and the equipment he needs



## Treasurer's List of Monies Received

The following are the cleared funds received by the treasurer of the Branch for the period October to December 2011, (NB: some figures have been rounded, all information was the best available at time of going to press).

### Fundraising events included: -

The Jolly Tanners Cricket Match, Staplefield	£173
Branch annual quiz night	£1,000
Lauren Head's coffee morning	£240
Quiz night at Handcross	£55

### Funds raised from sales: -

Mr & Mrs Roberts through sales of goods over the past year	£1,000
MND Association Christmas cards	£226
MND raffle tickets	£170
The bring-n-buy sale at the Christmas meeting	£112
Tea and coffees at branch meetings	£21

### Money from sponsored activities: -

A sponsored silence by Grace Howis and Stephanie Reed, aged 11-years	£21
Additional money from the half-marathon run by Sam Hopkins	£440

### Box Collections: -

Sainsbury's, East Grinstead	£448
Fabric Fair in Burgess Hill	£37
Fusion Hairdressers, Horsham	£15
Pub collection by Mrs Hopkins	£28

### Donations and gifts: -

The Sue Chapman Tribute Fund	£587
Plus Finance Ltd	£400
Albert Fry in memoriam	£245
Mr Robin Hughes	£200
Daren Stone memorial fund	£100
Mr & Mrs R Little	£50
Mrs Taylor	£25
Miss C. Diamond	£15

Thank you to everyone for their contributions. Every donation received makes a difference to a person living with MND.

## Welcome to our new Treasurer

MIKE ABBOTT has agreed to take over the role of committee Treasurer. 'We are extremely lucky to get someone like Mike after the departure of Alf,' commented Carol Rieley.



Mike, a resident of Lindfield, is an actuary who has spent his career in Financial Services. After qualifying, his corporate life was spent with a major unit trust, life insurance and pensions company where he became a director and Group Actuary.

From mid 1990s Mike was involved in a number of projects which led him to set up his own company specialising in the management of insurance schemes.

Today Mike's company business is active in several countries in the EEC as well as in the UK.

Mike has been involved in a financial capacity with a number of clubs and charities including; a local football club, a residents association and the National Childbirth Trust.

## Runners wanted for sponsorships

DO YOU KNOW anybody who is entering a marathon, half-marathon or fun run?

The branch would be delighted if they would choose The Motor Neurone Disease Association as their charity. We can help them obtain running vests and help them with their sponsorship.

Please contact Liz Carter who is running the Brighton Marathon in April for MND. Tel: 01444 232099.

## COMMITTEE MEMBERS

### President

Dr Steve Dyer

### Chairman

Carol Rieley  
01444 482387

### Vice Chairman

Chris Sheridan  
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### Secretary

Liz Carter  
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01444 450704

### Association Visitors

Chris Sheridan  
Linda Smilie  
Robert Mynors

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We would like to keep in contact with you about the important work we do. If you do not wish to receive further information please contact Carol Rieley

**mndconnect**  
**08457 626262**  
mndconnect@mndassociation.org

The MND Connect Team can advise you on all aspects of MND including symptom control, practical management, improving quality of life, clinical research, developing services and signposting to other care providers.

## Blue Badge Changes

CHANGES to the Blue Badge scheme in England are being introduced soon. Funding for assessing eligibility is shifting from the NHS, i.e. your local GP, to County Councils. In 2012 new applications and renewals of badges in West Sussex will be reviewed by a County Council medical assessor, unless you in receipt of higher-rate Disability Living Allowance (DLA) in which case the Blue Badge will be issued without assessment, although you still need to fill in the forms.

When asked if those diagnosed with MND, but not yet on the higher rate DLA, would automatically qualify for a Blue Badge, staff at the West Sussex County Council were unable to comment.

The maximum fee for issuing a badge will rise to £10 from 1 January 2012 (it has been set at £2 for over 20 years) to cover the cost of a new badge design meant to help prevent counterfeiting. **NB: There is no need to reapply for the new badge if yours has not run out.**

MND visitor Chris Sheridan pointed out that MND visitors can help fill in the forms. If individuals experience difficulties please raise these with your MND visitor, MND Connect, or with the National MND 'Cuts Watch' campaign manager Raj Johal, on Tel: 020 85512152.

The National Association says it is moni-

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**Telephone:** 01604 250505

**Email:** mndconnect@mndassociation.org

**Website:** www.mndassociation.org



From Page 1. Alf Bodimeade next to wife Jenny, retires as treasurer of the Branch.

toring the effects of these changes and will raise the issue with the Department for Transport, if necessary.

## Cuts Watch; My story

THE MND Association will shortly be launching 'Cuts Watch: My Story'. This involves people with MND telling their story, through a written or video diary, of how public services changes and cuts, that are happening locally, are impacting them and their families.

Do you have a story to tell? The National office of the MND Association are looking for people with MND who would be willing to take part in 'My Story' as a regular contributor.

As a 'My Story' contributor you will be helping to show other people in similar situations that they are not alone in facing similar challenges. Contributors can be anonymous if they wish. If you know anyone interested in telling their story please contact Raj Johal, campaigns manager, Email: [campaigns@mndassociation.org](mailto:campaigns@mndassociation.org), or Tel: 020 85512152.

**PASS IT ON**

Please pass this newsletter onto people who may be interested and together we will fight for our vision of a world free of MND.