

## September 2009

### Commemorative Floral Heart



In June, our branch commemorated friends and family lost to MND by making a beautiful heart shaped wreath, which was filled in with flowers given by people wishing to remember their loved ones.

Carol Rieley said, 'Instead of celebrating the lives of loved ones with balloons, we said it with flowers. Thanks are due to Carmen Eyre who told the committee about the Spanish tradition of laying flowers on the ground to form a heart in remembrance. Ours was smaller and portable but the end result was beautiful. John Rieley made the heart frame and Carol filled in the greenery and a few flowers before taking it to the Ark. Everyone brought along various 'favourite' flowers for the heart and the finished effect was stunning. Afterwards, it was transported to Turners Hill Church where it was left to be admired by the parishioners.'

'This was a lovely event making the most of the June weather to bring people together to celebrate the lives of those no longer with us. Everyone really enjoyed the day and the coverage in the local press really helped to raise awareness of MND.'

#### City Quiz in the Country

It's time to put your wits against each other again in this battle of the brains!

It's six to a team with Alf Bodimeade as our QUIZ MASTER!

Tickets cost £10 per person and include a hot supper. Drinks are available.

Venue - Princess Royal Hospital Social Club,  
Haywards Heath  
October 17th at 7.30pm

#### Diary Dates

If you need any help with transport  
**WE CAN HELP!** Please contact Carol  
Rieley on 01444 482387

27th September Anniversary birthday party  
tea at The Ark 3-5pm

6th October MND Association's 30th  
Birthday

17th October City Quiz in the Country

#### Lembit Opik Steps Down

Lembit Opik's father died of MND in 2005, and since then he has worked to secure £7.5 million of Government funding for MND research in his role as Patron of the association. Lembit said: "I believe that I leave the association with the momentum to deliver a cure, and that, ultimately has been my ambition."

We all wish him thanks and good luck for the future.

#### **In this issue:**

- MND Association 30th Anniversary information
- Introduction of new MND Association visitors
- Research: New MND gene found
- Marc Robson's amazing fundraising



## October 6th is the MND Association's 30th birthday!

To celebrate this special day the MND Association is organising lots of events across the country

- **Lanterns for Life** At 6pm on October 6th, people all over the country will be lighting a lantern. This can be a personal or a social event, and if you would like to share this with others, Carol Rieley has very kindly offered her garden as a place to come together. Please contact Carol for further information.



- **National Raffle** The raffle runs from June to October, and ticket stubs must be in by October 20th to stand a chance of winning one of the 30 AMAZING prizes, such as a Mediterranean cruise or **£3,500!!** Tickets cost £1 and can be ordered through the branch.

• **Pearl Ribbon** Commemorative Pearl ribbons have been created to represent 30 years of fighting for a world free of MND and to help raise awareness. Please contact the branch to order yours!



- **Christmas Cards** The cards are available to purchase from the MNDA catalogue and will be available from September on the MNDA website. Please have a look on: [www.mndassociation.org.uk](http://www.mndassociation.org.uk)

## Fundraising Updates

- **Marc Robson's** family and friends raised an absolutely amazing £6,159 with their LONDON to ARDINGLY walk - WELL DONE to all who participated!!!
- Sue Charman's tribute fund has raised another £361
- Bryan Thompson and his wife celebrated their **50th Wedding Anniversary** on September 5th and very generously asked for donations to MND Association instead of gifts on their special day. £200 was raised. On behalf of us all, THANK YOU very much
- The Cuckfield Ladies Club have chosen the MND Association for their charity of the year - Thank you!

## Liz Carter's Half Marathon

On Sunday 11th October our branch secretary Liz Carter is running the Royal Parks half marathon - 13.1 miles, in aid of the MND Association. The route starts and finishes in Hyde Park and goes through Green Park, Regents Park and Kensington Gardens. If you would like to sponsor Liz please call on 01444 232099, email: [elizabeth.carter209@btinternet.com](mailto:elizabeth.carter209@btinternet.com) or use the Internet [www.justgiving.com/LizCarter](http://www.justgiving.com/LizCarter)



## Waitrose Community Matters

Having been successfully nominated by Chris Sheridan as a charity to benefit from the Community Matters scheme run by the Waitrose Supermarket chain, our branch received £367 from the Burgess Hill store. Chris submitted the application with the intention of using any money raised to provide **pamper sessions** for those caring for people living with MND. As a result, three carers were able to enjoy a spa morning at the Alexandra House Hotel followed by lunch.

**There is still money available so if any other carers would like to have a pamper or therapy session, Chris would like to hear from you. Please contact Chris on 01444 245486 or email: [f.sheridan@sky.com](mailto:f.sheridan@sky.com).**

## New Gene Found Connected With MND

Following the identification of TDP-43 less than 12 months ago, and the discovery of SOD1 back in 1993, a collaborative research project between Kings College London and Harvard University, USA, has discovered a third gene called **FUS**.

A mutation in the FUS gene has been shown in 4% of people with the familial form of MND, which accounts for 10% of all cases.



The FUS protein - made by the FUS gene, is involved in many areas within the motor neurone such as the regulation of how messages are created, modified and transported so that proteins can be made. Normally, it is located within the nucleus of the cell, but when this mutation occurs, it is located on the outside of the nucleus where it forms large clumps or aggregates in the motor neurone.

Thanks to this new avenue of investigation, researchers will be able to compare different causes of MND and start to identify biochemical events which cause motor neurones to die and bring us closer to defeating MND.



### Sarah's Story

Sarah Ezekiel was diagnosed with MND in 2000 when she was 7 months pregnant with her second child. She is heading a hard hitting campaign called Sarah's Story, to described the emotional and physical impact of a diagnosis of MND. In a recent interview, Sarah says of the campaign "We've got to raise awareness because this will generate support, support will generate funds and funds will bring in the vital research we need to find a cure."

Her 90 second advert has been featured in cinemas across England and Wales, but was banned from TV coverage sparking much debate. It has also been advertised on London Underground billboards. To view Sarah's Story and show your support please go to [www.sarahsstory.org.uk](http://www.sarahsstory.org.uk)

### Walk To d'Feet MND by Chris Sheridan

I would like to thank all those brave souls (and two very well behaved dogs) who turned out again to support me on this years walk. I am always heartened and greatly relieved when such a large number turn up!

Our walk this year took place on Sunday July 5<sup>th</sup> - a beautiful sunny day, and not too hot. In all 22 people walked and, as in past years, it was good to see familiar faces but also to welcome new comers - I was especially delighted to see Helen and David Sivyer who had travelled from Hampshire to join us.

We met at Bolney and took a circular route passing Whykehurst Place and Bookers Vineyard before ending up at the village pub for a well earned drink!

Once again, it proved a very enjoyable occasion and also raised £200 for branch funds.

**Welcome** to **Kim Iliffe** our new Regional Care Development Advisor, covering Surrey and West Sussex. Also, to **Linda Smillie** and **Jill Shuker** our new MND Association visitors.

### NICE Announces NIV Start Date

The National Institute for Health and Clinical Excellence (NICE) announced that it started work on guidance for Non-Invasive Ventilation (NIV) in July of this year.

Guidance on NIV is expected to be published in the summer of 2010 and will be invaluable for influencing the provision of respiratory services for people with MND.

## 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

## Travel With Confidence

The MND Association recently removed its Holiday Insurance Information sheet in order to update it. In the mean time, if you require information on travel insurance, here are some key points:

When applying for travel insurance, people with MND will invariably be referred to a medical screening line and asked a series of questions which **may** include:

- Do you have a pre-existing condition?
- What type of MND do you have?
- How long have you been diagnosed?
- Have you been given a terminal prognosis?
- Are you awaiting any test results?
- Have you had inpatient treatment with the past three months?
- Questions about your independence



Other things to bear in mind are, that in insurance terms, terminal diagnosis usually means you have been given less than six months to live. We advise you to say yes, you have been diagnosed with a terminal illness, but make it clear you have **NOT** been given any prognosis.

The question about test results will not refer to routine tests carried out during a check up. However, if you are awaiting other test results, you will **NOT** be offered cover.

Insurers do not like to offer cover to anyone who has received recent inpatient treatment. Also, they may add a high excess to premiums if you were diagnosed over 12 months ago.

The MND Association strongly recommend you obtain at least three quotes and go for the most competitive, keeping in mind this advice, and when you receive your policy check it carefully! Also, if you're taking equipment and aids, think about getting them covered as well.



**Helpline:** 08457 626262

**Email:**  
mndconnect@mndassociation.org

**Website:**  
www.mndassociation.org

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

**Regional Office:** David Niven  
House, 10-15 Notre Dame Mews,  
Northampton, NN1 2BG

**Telephone:** 01604 250505

## Blue Badge Information

To receive FREE details for Blue Badge drivers, on parking, RADAR toilets, shop mobility centres and much more visit:

**England:** [www.direct.gov.uk/BlueBadgeMap](http://www.direct.gov.uk/BlueBadgeMap)

**Wales:** [new.wales.gov.uk/topics/transport/Integrated/Transport/BlueBadgeScheme/?lang=en](http://new.wales.gov.uk/topics/transport/Integrated/Transport/BlueBadgeScheme/?lang=en)

**Northern Ireland:** [www.roadsni.gov.uk/index/bluebadge.htm](http://www.roadsni.gov.uk/index/bluebadge.htm)



## Treasurer List of Monies Received

DC	£18.56	SC Tribute Fund	£361.03
City Quiz	£11,783.00	Burgess Hill Fabric Shop	£34.82
CE	£15	Horsham Street Collection	£1,237.31
Waitrose	£367.03	Haywards Heath Street Collection	£832.58
MR	£5,635.50		