

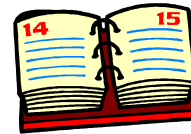
**MOTOR NEURONE
DISEASE
ASSOCIATION**

**WEST SUSSEX - NORTH BRANCH
NEWSLETTER**

January 2006

HAPPY NEW YEAR

Diary Dates



Branch Meetings

Tuesday 7th February

Speaker, **Jonathon Baldwin**, Chaplain
at Gatwick Airport.

*Handcross Park School
8pm*

AGM

Tuesday 25th April

Dr Kirstine Knox, Chief Executive, will be
our speaker. All are welcome. Bring family
and friends to this special event. The
formalities will be short and there will be
wine and cheese.

The Parish Hall, Handcross - 8pm



Fundraising

Monday 27th March
Quiz in the City

The Barracuda Bar, London

EXCITING FUNDRAISING EVENT



Saturday 18th February

The Parish Hall, Handcross

8 pm

We are delighted to announce that Simon Brett, writer of novels, plays and serials and performer on the radio programme "Quote, Unquote", has agreed to perform a one-man-show for us. It will take the form of a murder-mystery story-telling evening and all of you who enjoyed his talk at last year's AGM will know we are in for a highly entertaining evening. There will be wine and a buffet and all this for only £10 a ticket. We need to sell lots of tickets so please spread the word. Tickets can be obtained from Carol Rieley. Tel: 01444 482387.

Fighting
Motor Neurone Disease



*Our Thumbs Up symbol represents David
Niven's last defiant gesture. It remains
our symbol of hope.*

Report of October branch meeting

For our October meeting, we were lucky to have two very interesting speakers. Our first was **Charis Diamond** who looks after the spiritual care at *St Catherine's Hospice*. Charis was a Speech and Language Therapist specialising in children and after taking early retirement, she did a course in theology and pastoral care. Since being granted a Bishop's licence, she has worked at St Catherine's two days a week for four years. She told us that the word 'hospice' derives from the word 'hospitality' and dates back to the 4th century when it meant a house situated on pilgrim ways where pilgrims could receive rest and refreshment along with care when they were sick. Later, they were set up to care for people who were near death. The modern hospice movement was started by Dame Cicely Saunders who opened the first hospice in Sydenham in 1967. There are 280 hospices in this country and the movement has spread to 100 countries over the world. Palliative care has now been recognised as a discipline in its own right.



St Catherine's Hospice specialises in palliative care for people with a progressive life-limiting illness which will not respond to treatment like advanced cancer and also MND. There are two wards with a total of 24 beds and also a Day Hospice which offers support, some therapies and gives people a change of scene. It also reaches into the community and cares for people at home. Charis' rôle is to assess and look after spiritual needs and to support patients, relatives and staff with the big questions about dying. She said she does not have all the answers but can offer help relieve the anguish when people find it difficult to come to terms with what is happening. She establishes a relationship with them and sometimes they can share their feelings. Doctors and nurses do the same but are very busy. She has the luxury of being able to spend a long time with patients. Sometimes there are no words or actions for her to take but it just helps to be there and sometimes she just sits and takes their hand. She told us that the greatest compliment to pay another person is to listen attentively and retentively.

Our next speaker was **Steve Dyer** who is the Consultant in Palliative Care at *St Peter & St James Hospice*. He told us that he qualified as a GP thirty years ago and was in practice in Milton Keynes. He enjoyed working with people and finding a way to resolve the problems brought to him. He was introduced to hospice work when the practice was asked to look after the local hospice. He did a course and found out all he could and, eventually, having tried to do half of both jobs, he had to decide whether to stay as a partner in the GP practice or to be an employee of the local hospice. It was a difficult decision but he chose the hospice. He found it a very different way of life. Now he worked in a team with nurses, social workers, a chaplain and many fewer patients. He realised how important good care is at the late stages of life. Steve arrived at St Peter & St James nearly three years ago and his rôle has been to develop the palliative care service in Mid Sussex. He said that each hospice has its own distinct feeling and that St Peter & St James is slightly different in that, as well as having patients for a short while, they also have people for a longer time, sometimes several years. They seek to provide an environment which is a home from home in beautiful Mid Sussex woodland with a view of the South Downs. He told us that the growth of the hospice movement is remarkable and, in this country, we are at the forefront. He has huge interaction with other countries and sees how different their hospices are. He has given periods of two weeks' experience to foreign doctors and nurses and said it has been a privilege to see the transformation it has made to all prestigious doctors from other countries. He also visits other countries and uses interpreters to teach them about palliative care. He is always impressed by the need and willingness to learn

At the end of the meeting, we were addressed by two visitors from National Office; Colin Byer who is Financial Controller and John Blake who is Head of Support and Development in the Fundraising Team. They gave us a slide show illustrating how the finances are organised and congratulated us for being in the top 20 out of 80 branches in terms of fundraising.

Report of December branch meeting

Our Chairman, Carol Rieley, started the meeting by announcing that our branch had received a 'Starfish Award'. This had been accepted on our behalf by Bridget Gosney at a regional meeting and had been presented to us for innovative and well-attended AGMs and for very successful fundraising.



Our speaker was committee member, Anna Shaw, who gave an interesting talk, accompanied by some lovely slides, about her wonderful experience doing an MNDA challenge, riding in Rajasthan. The eleven people on the trip, seven of whom were supporting the MNDA, were riding a native breed of horse called Marwari which are bred for stamina and speed and are small and dainty but very agile and strong. They rode for five days in quite hot temperatures but Anna said it was comfortable because it was a dry heat. The terrain was quite rough and also hilly in places but the horses were very sure-footed. All along the route, the party caused quite a stir because it is so unusual for Western people to go there to ride. In fact, they were filmed by a local film crew. Anna was delighted to be able see camels and elephants while she was there and part of the route was through a wildlife sanctuary but the horses made too much disturbance for them to see much wildlife! In total, £23,500 was raised for the MNDA and Anna herself raised over £3,000. She said "It was a fantastic experience of a lifetime and lovely to know that we were raising money for such a good cause".

DNA Bank

The MND DNA Bank is the most ambitious research project ever undertaken by the MND Association. It aims to collect several thousand DNA samples over five years, the resulting information being used by research scientists as they investigate potential causes of and possible treatments for the disease. Donors include people with both the sporadic and familial forms of MND, family members and ‘control’ samples from others unrelated to people with MND or their families.

If you are interested in donating a DNA sample (this is obtained from a blood sample), you need to fulfil the following criteria. You should be a person with MND, diagnosed (or experiencing symptoms) after 1st January 2002, or you should be linked to such a person. For more information, contact the Research Development team at National Office on 01604 611880.

New website launched



If you haven't had a chance to visit www.mndassociation.org lately, then make a point of having a look. It has been designed to better meet the needs of people with MND, their families and all others involved in their care and support. The site is bigger and brighter with more functionality, features and with easier navigation and accessibility.

Free Flights



John Middlemass loved to fly his four-seater Piper Archer and when, due to his MND, he was no longer able to pilot the plane himself, his good friend, Bill Manley, stepped in and took John on many enjoyable flights.

John sadly died in 2003 and Jenny, his wife, hated to see his beloved plane standing unused. Bill offered to give people free flights in the plane and many people affected by MND in the Hertfordshire area have taken advantage of the offer.

Jenny, with Bill's assistance (!), would like to offer this opportunity to other people affected by MND. If you are interested, please give Bill a ring on 01763 244397.

Adults of any age and children (accompanied by an adult) are welcome.

MONIES RECEIVED SINCE SEPTEMBER

| | |
|----------------------------------|--------|
| Anne Kirwan | £ 20 |
| Mrs P Greenfield | £ 50 |
| Mr and Mrs Roberts | £ 500 |
| Books and Bangles (Carol Rieley) | £ 64 |
| Pam Hoskins and family | £1,000 |
| Mr and Mrs Robinson | £ 450 |

Stay Safe on the Roads in Winter

Drivers are advised to follow seven key ‘safe driving’ messages during the winter months. These are:

1. Before setting out on a journey, ask yourself “is it absolutely essential?”
2. Check local and national weather forecasts. Listen to travel information on the radio.
3. Clear your windows and mirrors before you set out and carry a screen scraper and de-icer.
4. Take care around gritting lorries and snowploughs. Don't be tempted to overtake snowploughs by squeezing into partially cleared lanes.
5. It can take ten times longer to stop in icy conditions. Allow extra room to slow down and stop.
6. Use the highest gear possible to avoid wheel spin. Manoeuvre gently to avoid harsh braking and acceleration. If you start to skid, gently ease off the accelerator and try to avoid braking. If braking becomes necessary, brake very gently.
7. When driving in snow, make sure you are equipped with warm clothes, food, water, boots, a torch and a spade.

West Sussex Carers' Emergency Alert Card

Do you worry about what would happen to the person you look after if you were taken ill and unable to tell anyone that someone depends on you? If so, the West Sussex carers' emergency alert card scheme may be of help.

The scheme provides you with an emergency card that shows someone depends on you. If anything happens to you while you are out, the emergency services will be able to alert someone you know about what has happened. This means that when you have to leave the person alone (at home or in the car) you both can have some peace of mind.

The scheme is free for carers. All they ask is a couple of first class stamps towards postage.

Over 1400 carers in West Sussex have registered with the scheme and the scheme is much valued. It is funded by West Sussex Social and Caring Services, administered by ICIS and supported by District and Borough Councils, Emergency Lifeline Services and health services in West Sussex.



For a leaflet and enrolment form, write to:

ICIS
35 Worthing Road
East Preston
West Sussex
BN16 1BQ
Tel: 01903 859929

Branch Meetings

Meetings are held at Handcross Park School, at 8 pm.

2006 dates are:

7th February 3rd October
6th June 5th December

MOTOR NEURONE DISEASE ASSOCIATION

HELPLINE – 08457 626262
(all calls charged at local rates)

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