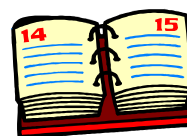


May 2006

Diary Dates



Branch Meetings

Tuesday 6th June

Our speaker – *Jenny Rimmer*,
will be giving a talk about Iridology
entitled '*The Eyes Have It*'.

*Handcross Park School, Handcross
8 pm*

Tuesday 3rd October

Our speaker – *Liz Abraham*,
will be giving a talk about back care
entitled '*Watch Your Back*'.

*Handcross Park School, Handcross
8 pm*

'Walk D'Feet'

Sunday 2nd July

Easy 5 mile walk organised by Chris Sheridan

*Phone 01444 245486 for
venue and details*

Street Collections

Saturday 24th June

HORSHAM

Saturday 22nd July

HAYWARDS HEATH

**21st National AGM
and Annual Conference**

16th and 17th September

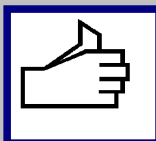
Hilton Birmingham Metropole

**17th International
Symposium**

30th November to 2nd December

Yokohama, Japan

Fighting
Motor Neurone Disease



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

Report of February branch meeting



Jonathan Baldwin gave us an interesting account of his unusual and demanding job as the chaplain at Gatwick Airport. Sussex born and bred, Jonathan left school at 16 and worked in Lloyd’s Bank. While working in the bank, he was fostering a vocation to the priesthood and, in 1992, the bishop sponsored him to train in Chichester for two years. After qualifying, he worked in Crawley as a deacon and in Shoreham as a curate and has worked at Gatwick Airport for nearly four years.

He told us that most of his time is spent with the huge number of staff and not the passengers. He works alongside firemen, policemen, cleaners etc. doing their shifts and getting to know them. He listens to them and they can get to know him so they feel they can approach him. He said it is important to be seen and be part of the community. There are two chapels in Gatwick Airport. The larger one, which was consecrated in 1976, is in the South Terminal on the first floor and the other has been on the ground level in the North Terminal for just over ten years. He tries to have a daily Holy Communion Service. He has carried out baptisms and services to renew wedding vows. Gatwick Airport has two newspapers and the chaplain has a column in them letting staff know about the chapels and offering support and a listening ear.

He does care for passengers too. He comforts and prays with people nervous of flying or who have family worries. He meets lots of distressed and burdened people and also deals with quite a few homeless people who decide to make the airport their home with its 24-hour warmth and many food outlets.

Jonathan is also on the committee of a charity called “Travel Care”. This charity was originally set up to help lots of distressed Irish women who came over here for abortions when it was not legal in Ireland. The charity helps people with other travel problems such as stolen bags or money. Anyone in desperate need can be given a bus or train fare or money for a telephone call. It is all manned by volunteers.

Jonathan said he loves his job because Gatwick Airport is a dynamic and exciting place to work.

Simon Brett

A hugely entertaining and unusual fundraising evening was well-attended at Handcross Parish Hall in February when Simon Brett performed ‘Lines of Enquiry’, his very humorous play which was full of all the clichés found in police and detective television programmes and was completely in verse. Simon acted all the characters who all had different accents. He also included sound effects made by the pathologist performing a post-mortem which were so realistic that they made a few people wince! Copies of his very witty programme were distributed which listed the supposed actors and production team, all of whose names were anagrams of *Simon Brett*. Afterwards, we enjoyed a buffet and drinks and Sue Taylor and her friend kindly ran a raffle. In all, £745 was raised.



Branch AGM - 25th April

Around 35 people attended the AGM. In her report, Chairman, Carol Rieley, thanked everyone for their sterling efforts over the past year, especially Alf Bodimeade who organised the ‘Quiz in the City’ which raised an impressive £8,300. She told us that Simon Brett had kindly agreed to become our first Branch Patron. All the committee were prepared to stand again but Nick Cottom would stand down as Vice Chairman while remaining a committee member and Christine Sheridan was elected to join the committee. Vijaya Shetty would be standing down in a year’s time so an appeal was made for someone to consider filling the gap of secretary next year.



It took 10 minutes for the business to be completed and then Carol introduced and welcomed our speaker, Dr Kirstine Knox, who became Chief Executive of the MNDA last July. Dr Knox told us that, since joining the Association, she had been inspired and humbled by the dignity and courage shown by everyone living with MND and their families and friends and the hard work and determination of the volunteers. This was an evocation of her Scottish Socialist upbringing. She said we are the key to the Association’s success.

She entitled her talk ‘A World Free of MND’ which is her vision. She is a scientist by training and is excited to be part of a group of energetic and committed people at the start of the end of MND. She said that recent science has changed so much that it could be possible, citing progress in treating AIDS where new drugs mean that it is no longer a death sentence. Dr Knox thinks this could happen with MND but research is expensive. She would like to see the new drugs coming from America for clinical trials here and said the MNDA must spend more money on research but not at the expense of care.

There are lots of charities vying for money and the campaign, ‘John’s Journey’, was extremely successful in bringing awareness and opened the door to involving a group of super-rich people who have promised to raise £6m. To this end, Dr Knox wrote the publication “Vision for the Future” and is going to meet the Prime Minister to enlist his personal support and ask for No. 10 for a reception. There will also be fundraising for palliative and end of life care in all parts of the country as she believes everyone is entitled to the best care as near to home as possible. She told us that, in some parts of the country, care is appalling and the MNDA provides a safety net which it is seeking to strengthen.

Dr Knox ended by congratulating and thanking us for the fantastic work we all do and then answered questions.

monday, the charities lottery



The Association's website has been updated recently to promote our new lottery partnership with *monday*, the charities lottery. The MND Association will be one of 70 charity partners to benefit from this new online lottery that hopes to raise over £150 million for UK charities each year. Charities will get 30% of every ticket sold - more than five times what they received from every National Lottery ticket. Players, too, will benefit with better chances of winning a jackpot and higher prizes for matching fewer numbers.

Under the Association's agreement, *monday* will be responsible for marketing and running the lotteries and selling the tickets. The MNDA will be responsible for promoting the lottery to supporters in order to generate ticket sales and, in return, will benefit from five lotteries a year with the potential to earn up to £600,000 from each one. The MNDA are keen for this wonderful opportunity to be a success and are appealing to everyone to support this new lottery, particularly in the first few months.

Benefit changes

From April 2006, more people should qualify for Income Support, Housing Benefit and Council Tax Benefit. This is because the capital limits have increased for these benefits, allowing people to have more savings when they claim. From April 2006, only capital above £6,000 will be taken into account instead of £3,000 previously and the upper limit for savings before you are unable to claim is £16,000, increasing from £8,000.

MONIES RECEIVED SINCE JANUARY

Brighton Road Baptist Church	£ 130
Simon Brett Evening	£ 745
Chailey Bowling Club, per Mr and Mrs Sheridan	£ 25
Jenny Rimmer (Hat hire/sales)	£ 200
In memoriam donation re Mrs Fry	£ 425
Quiz in the City	£8,300




Jimmy Johnstone 1944-2006

Jimmy Johnstone, who lost his fight against MND on 13th March, aged 61, was a legend in Scottish football. Since his diagnosis in 2001, Jimmy did much to raise the profile of Motor Neurone Disease and to raise money to support people with the disease. There are plans to make a charity single to be released as a tribute to Jimmy, with proceeds coming to the MND Association. The main track is set to be a version of *Dirty Old Town* sung by Jimmy and Jim Kerr of Simple Minds.

Patient Opinion

Patient Opinion is a new website where you can see what other patients are saying about your local hospitals and you can share your opinion too. It is independent of the NHS, free to use and is run on a not-for-profit basis. Go to www.patientopinion.org.uk. If you do not have access to the Internet, you can call 0845 113 0012.

Majestic Wine Warehouses

Majestic is supporting the MND Association in 2006. It has placed collection warehouses and will be wine tasting events to raise more funds.  boxes in all its wine holding special throughout the year Majestic raised a staggering £8,500 in just over two months – well on its way to reaching its £40,000 target.

Could you be paying less Council Tax?

A reduction in the amount of Council Tax you are paying could be applied for if you, or any adult resident in your home, is 'substantially or permanently disabled'. The scheme is not means tested and, if you are entitled to other help with Council Tax, you may still claim this reduction. For more information, please contact the Helpline.

Mental Capacity Act 2005

The Mental Capacity Act governs decision-making on behalf of adults, where they lose the capacity to make or communicate a decision at some point in their lives or where the incapacitating condition has been present since birth. Examples include a learning disability, brain injury or mental health problems. The key parts of the Act are Living Wills, Code of Conduct and Lasting Power of Attorney (LPA).

Living Will. A Living Will is when you can make a decision now about treatment you would want in the future when you have lost capacity. This is not a legal document.

The Code of Practice. This is a guide to how the Act will be implemented.

Lasting Power of Attorney. An LPA is when someone acts on your behalf to make decisions for you. There are two LPA forms which cover property and personal welfare. There can be five LPAs appointed for one person. Restrictions and conditions can be placed on the LPA. LPAs will be able to take all decisions about the person's welfare. They won't be able to make decisions about life-sustaining treatment as this will be covered in the Living Wills. LPAs cannot be made jointly or on behalf of someone as they need to have the capacity to do this. Any objection of an LPA would need to be made within five weeks. An LPA is a legal document. An essential part of the process is to provide a statement of certificate provider (an independent person who certifies that the person making the LPA understands what they are doing).

The Act, Code of Practice and LPA will be in force from April 2007.

Branch Meetings

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

2006 dates are:

6th June

3rd October 5th December

MOTOR NEURONE DISEASE ASSOCIATION

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