



Multiple Sclerosis Society

Registered Charity No 207495

Oxford and district branch Newsletter

July/August 2010

Dear Friends

Our membership secretary, Stevan Heads, became a media star when he appeared on BBC local radio and TV and in the Oxford Mail in the space of two days commenting on the decision of the National Health Service not to make available the cannabis-based pain relieving drug, Sativex, in Oxfordshire.

The NHS will not routinely prescribe the mouth spray for patients in the county because, it says, there will no evidence that it is effective.

Stevan told listeners, viewers and readers that he took Sativex for about 10 years as part of a drugs trial and said it significantly reduced the symptoms of his MS.

He said: "It totally reduced my pain - I felt no pain at all when I was on it. It also reduced the spasms by about 90 to 95 per cent. I have noticed an increase in both the pain and spasms since I stopped taking Sativex."

Sativex is sprayed under the tongue up to 12 times a day and costs the NHS £125 per 10ml vial, which works out on average at £11 per person per day.

Trials have found it to reduce spasms and sleep disturbances in 40 per cent of people with MS.

However, the priorities committee for the South Central NHS region has deemed it a "low priority" for funding. Only those in exceptional circumstances will be given the spray by NHS Oxfordshire.

The committee said the evidence for Sativex and similar drugs in clinical and cost terms was "currently insufficient to support their use."

Jayne Spink, director of policy and research for the MS Society, said the decision was disappointing.

She said: "We'd like to see Sativex made available to anybody who might benefit."

OPEN DAYS

By now, all members should have received a questionnaire asking for their opinions on our Open Days. If you haven't, a copy is attached to this newsletter. We need to know from you what changes, if any, we need to make to the format of the day to make it more appealing.

We meet at the Northcourt Centre in Northcourt Road, Abingdon, on the first Friday of the month (except January). At present, we have a speaker or entertainer at 10.30am, lunch at midday, then therapists from 12.30pm. There is plenty of time to chat and relax in the lounge. Lunch and therapy are free - all you have to pay for is a raffle ticket if you wish.

However, out of a membership of about 190, numbers have dwindled to below 20. Every Open Day costs the branch about £1,000 - rent, transport, speaker/entertainer, lunch, therapy and Crossroads carers - and the branch committee considers this is too much for so few people.

We need to know why members are not attending our Open Days and what we need to do to make them more attractive to encourage them to come along.

Please make sure you fill in your questionnaire - your views are important.

At our June Open Day, we were pleased to welcome musical duo Diane and Ian Woods, while in July, our guest was Wesley Smith, the well-known TV and radio presenter.

Diane and Ian kept up tapping and singing with a series of popular songs, and Wesley left us spellbound as he spoke, in his inimitable relaxed style, of the opportunities that had opened up for him, on radio and in media training, following his shock redundancy from ITV regional news. Our thanks to them for coming.

At our August Open Day, we welcome back the popular Don Rouse, from Lew, near Bampton, who will regale us with more of his amusing village tales. In September, there will be a singalong with keyboard player David Clark, while in October, the musical theme will continue with a visit from the Oxsrads Choir.

In November, our fundraiser, Brenda Franklin, will lead a workshop during which members will be able to make their own Christmas cards. All Open Days will be held at the Northcourt Centre in Northcourt Road, Abingdon. The dates are listed later in the newsletter.

ARE VEINS THE KEY?

Branch member Mark Walker was the subject of a Daily Telegraph feature, following a visit to Athens for revolutionary treatment on his MS.

An Italian surgeon, Professor Paolo Zamboni, whose wife Elena has MS, has put forward a new theory about its cause. His conclusion is that MS isn't only an auto-immune condition, but also a vascular one, caused by restricted, blocked, malformed or twisted veins in the trunk and neck. A small study showed that 90 per cent of his patients had venous obstruction.

He named the condition chronic cerebrospinal venous insufficiency (CCSVI) and suggested the answer was to unblock - or de-stenose - the restricted veins so that healthy blood-flow could resume. The effect, it is claimed, was a dramatic alleviation of symptoms in Zamboni's wife and in subsequent patients he treated.

News of Zamboni's approach spread among the MS community. Vascular surgeons in private clinics in Poland, Bulgaria, Greece, Germany, Belgium, the United States and India are now offering diagnostic tests to confirm the presence of stenosed veins, and surgery to

unblock them, with waiting lists growing by the day. Anecdotal reports suggest that treatment stops relapses in some patients, and eases symptoms and halts the disease's progression in others. Neurologists at the John Radcliffe Hospital in Oxford ruled out similar tests on the grounds that they were not ethical or prudent. So Mark spent £7,000 to travel to Athens, where surgeon Constantinos Kartkaletsis diagnosed four 'restricted' veins and cleared them.

Surgery for CCSVI has had some negative publicity - one woman died in California - but Mark says this should be put in perspective - about 1,000 procedures have been carried out so far. He believes there is a "turf war" between neurologists who believe they "own" MS, and radiologists and vascular surgeons who may have something to contribute to its management. Patients are being caught in the crossfire.

He told the Telegraph: "Neurologists have been treating MS with powerful drugs for decades. Despite this, many patients suffer continued progression of their disease. Others give up the drugs because of side-effects. Treating any CCSVI symptoms is worth a try for many people." We will update you on Mark's progress in future newsletters.

BOAT TRIPS

Our first 'voyage' of the year aboard The Venturer, the adapted narrow boat, on the Oxford Canal and River Thames had to be cancelled because none of the crew had been issued with their safety certificates.

However, the problem was resolved in time for the second trip, on Saturday, 12th June, to go ahead as planned, with a full contingent aboard. The final trip of the year is booked for Saturday, 7th August.

Call Jeff Samways on **01235 520231** for any queries about boat trips.

HELP AT HAND

Drugs can sometimes make you thirsty, and you may find it difficult to get easy, independent access to drinks. If so, the Hydrant may be just what you are looking for.

It is a low-cost, personal drinking system that gives the user instant access to drinks without having to reach out or call for help.

Drinks are fed from a bottle through a drinking tube. A simple device allows the bottle to be attached to beds, chairs, wheelchairs, in fact, almost

anything.

A one-litre system costs £12.95, a 750ml system £11.95 and a cleaning kit £8.99. For more details, call **07813 012779** or go to www.hydrateforhealthco.uk

We will have the Hydrant on display, as well as leaflets, at our next Open Day.

GETTING LOUD

The MS Society is planning a mass lobby of Parliament, to make sure its voice is heard by the new coalition Government.

After a buffet lunch, delegates will meet MPs and tell them about the services and support people affected by MS need to lead full and independent lives. Later, a reception will be held to launch the society's manifesto, urging everyone to 'get loud'.

FUN DAY

The Thames Valley MS Society summer fun day takes place at the Cotswold Wildlife Park at Burford on Sunday, 1st August.

Information about how to book came too late to be included in the last newsletter. The closing date for free tickets has now passed and we are sorry if anyone is disappointed. But you can still join in if you pay.

ROBBER JAILED

A woman who befriended, then robbed branch member June Stephen, was branded “a menace to society” and jailed for three-and-a-half years.

Clare Thomas, 25, and a male friend came to June’s rescue when she collapsed in the street, helped her into her home and waited for a carer to arrive. But two days later, Thomas returned, cooked dinner for June, then pushed her into a cupboard and stole her laptop.

Judge Patrick Eccles, sitting at Oxford Crown Court, told Thomas, who had 11 previous convictions, including one stabbing, that she had a “terrible lifestyle”.

He said: “You are a woman with a truly shocking record for breaking the law. You knew from the victim’s appearance that she was disabled and suffered from MS.”

June told the court that she could smell alcohol on Thomas’s breath and was wary of her presence, but her attacker was insistent she should stay. In a victim impact statement, she said she now felt “even more vulnerable”.

She said: “Because of my

disability, I really rely on my laptop. I have suffered stress and anxiety and now have to double-lock my doors and will no longer open them to strangers.

“I have been worried about identity theft because of the laptop. Sorting out a replacement has been difficult because I am disabled.”

Peter Coombe, defending Thomas, trotted out the usual lame excuses that lawyers use in these cases - Thomas had had a difficult childhood, had been abused and had been on hard drugs.

Thomas showed no compassion to June - and thankfully, the judge showed her none either!

HANDY GUIDE

A new book, Multiple Sclerosis - The Essential Guide, has recently been published.

It delivers clear and easy-to-understand information to those who have just been diagnosed with MS, as well as to friends and family who want to know more about the condition.

To order a copy, phone **01733 898103**, email sales@n2kbooks.com or you can order through the website, www.need2knowbooks.co.uk

BRIEFLY

We were sorry to hear of the death of branch member, George Trafford. Our sympathy goes to his family.

One way members can help the branch to cut costs is to receive the newsletter by email, thus saving us printing and postal costs. If you would like it to be sent electronically to your computer, send you email address to our membership secretary, Stevan Heads, at s.heads@ymail.com

Research shows that the MS Society's latest advertising campaign reached more than 24 million people across the UK, seven million more than last year - and on a tighter budget.

The MS Society direct marketing campaign, to increase membership and raise money, during MS Week was a great success. More than 1,800 new supporters were recruited and they made donations of more than £160,000.

Teresia Paige sends her best wishes to all members of the branch.

A party of branch members attended an evening at Wantage Civic Hall, where TV and radio presenter interviewed Colin

Dexter, author of Inspector Morse. The event was in aid of the Alzheimer's home at Botley.

Chris Lima has been co-opted as our new Support Officer, looking after welfare matters. We will introduce you to him in our next newsletter.

Mark Osborne, whom we featured in the last newsletter, has set off on his round-the-world cycle ride to raise money for MS. The personal fitness trainer is now on the first leg of his journey to Greece. We wish him well.

Let us know if you hear of anyone ill or in hospital. Call **0779 237 7178** for all welfare matters. Send correspondence to John Chipperfield at 3 Lambs Close, Kidlington, Oxon OX5 2YD. For the MS nurses, call **01865 234461** or email ms.advice@orh.nhs.uk Call **01865 231869** for information about ongoing and new MS trials.

To contribute to the newsletter, call John Chipperfield on **01865 374877**, write to 3 Lambs Close, Kidlington, Oxon OX5 2YD or send an email mjpchipperfield@yahoo.co.uk

All views expressed in this newsletter are individual and not necessarily the view or policy of the charity or its supporters.

DATES FOR YOUR DIARY

Sunday August 1: Thames Valley Region fun day, Cotswold Wildlife Park, Burford.

Friday August 6: Open Day, Northcourt Centre, Abingdon. Speaker: Don Rouse on amusing tales of village life. 10am-4pm

Saturday August 7: Trip on The Venturer on the Oxford Canal and River Thames.

Friday September 3: Open Day, Northcourt Centre, Abingdon. Organist David Clark entertains. 10am-4pm

Friday October 1: Open Day, Northcourt Centre, Abingdon. The Oxsrads Singers entertain. 10am-4pm

Friday November 5: Open Day, Northcourt Centre, Abingdon. Brenda Franklin's workshop on making Christmas cards. 10am-4pm

Friday December 3: Open Day, Northcourt Centre, Abingdon. Speaker to be announced. 10am-4pm.

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NO OPEN DAY IN JANUARY

Saturday January 15: New Year lunch, Thames Four Pillars Hotel, Sandford-on-Thames. Booking form will be issued soon.

Friday February 4: Open Day, Northcourt Centre, Abingdon. Singer/guitarist John Hobbs entertains. 10am-4pm.

Friday March 4: Open Day, Northcourt Centre, Abingdon. Branch annual meeting. 10am-4pm