

## **South Herts Branch**

### **OCTOBER 2012 NEWSLETTER**



**Lesley Ralston collecting a cheque for £627  
from the Rickmansworth Waitrose Communities Matters Team**

## Patron - Dr Carol Scholes

Macmillan Consultant in Palliative Medicine in the Community

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MND  
**connect**  
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## CHAIR'S REPORT OCTOBER 2012

Well this fantastic summer is on the way out, but what wonderful memories we are left with. The Olympics and Paralympics have been inspirational. I was one of those who grumbled about the cost/was it going to be ready/did we WANT if anyway/could we even do it/was I interested. Well – it was worth the cost, it was ready well on time *and* on budget, *of course*, we of all countries, could do it and, *boy* was I interested! I was glued to the box every day and had such a sense of pride and excitement.

Miraculously (*really miraculously*) the weather was perfect for both games. Not sure how to explain that one !!

I was at the Paralympics last week watching swimming and had a fantastic time. The Olympic park was spectacular, the swimming was inspirational and the noise deafening! Had a lovely walk and the planting is beautiful - and we unexpectedly saw the Jubilee Barge moored on one of the canals in the park – glittering gold and red.

We recently had our Tring Brewery visit and there is a report in the newsletter about it. It turned out to be an enjoyable evening with as much beer as you could drink!

If you have not already done so, please do consider coming to our carers and ex carers coffee club. It is held at the Inn on the Park café in St Albans Verulamium Park and the next date is at 11am on Wednesday 3<sup>rd</sup> October. Some special friendships have been made and we spend a really nice couple of hours all chatting. We can all help each other in so many ways and talking is the best way to do it. If you want to ring beforehand, please do, on: 01923 778990 – I'd be delighted to have a chat. Please don't feel daunted – it's amazing how helpful this sort of socializing can be.

On Wednesday 10<sup>th</sup> October we are having a social evening when there will be a speaker talking about The History of Newgate Prison and the Old Bailey – which I think will be very interesting. The speaker is a London Tour Guide - [www.london@yourfeet.com](http://www.london@yourfeet.com) - and she tells me the talk can be funny and gruesome !! I am personally fascinated by that time in history – Dickens and all that – and am really looking forward to it.

There will be light refreshments.

We shall also have a raffle, and if you would like to buy any of the MNDA Christmas cards and gifts, and also birthday cards now - they will be on display.

Then we shall have our Christmas party at The Noke hotel as usual on Wednesday 5th December at 7pm. There will be mince pies and tea/coffee – and the bar will be open if you would prefer something jollier. We are hoping to have a choir again this year, but that is to be confirmed. Do hope you can all come and join us for that.

Again, there will be a raffle and a last chance to buy Christmas cards and small gifts.

South Herts Branch will be selling Christmas cards and small gifts at the Watersmeet centre in Rickmansworth and also at the Berkhamsted Christmas card fair before Christmas. Further information and dates in the newsletter.

Lesley

*You can tell Monopoly is an old game - the banker can still go to jail.*

## **EDITOR'S NOTE**

If you would like to receive the newsletter by email, to help cut our costs, then please let Jennifer Hay know at [rollewisjenhay@gmail.com](mailto:rollewisjenhay@gmail.com)

## FUTURE EVENTS

**Wednesday 3 October at 11am**

**Coffee morning for carers and ex-carers**

Meet at the Inn on the Park, Verulamium Park, off St Michael's Street (which is off Hemel Hempstead Rd A4147), St Albans, AL3 4SN. Park in the Museum car park, £1.



Next date for carers meeting.

**November 28 2012**

**Wednesday 10 October 7pm - Social evening  
(note 2<sup>nd</sup> Wednesday in the month)**

Come along to The Noke Hotel and listen to a talk on The History of Newgate Prison and the Old Bailey.

Also your chance to buy MNDA Christmas cards, and no postage to pay !

**Saturday 13 October 10am to 1pm**

**Autumn Market, Watersmeet Theatre, Rickmansworth**

Come along to our stall for Christmas cards and small gifts.

*Hedgehogs - why can't they just share the hedge?*

## **Wednesday 17- Thursday 18 October 2012, Naidex South ExCeL London**

Register now for your free ticket to Naidex South; where you go to overcome daily living difficulties for long-term conditions. The event for inspirational independent living

[www.naidex.co.uk/south](http://www.naidex.co.uk/south)

### **KEY REASONS TO ATTEND NAIDEX SOUTH**

- Uncover 100s of inspirational products. Touch, test and compare the latest innovations from over 150 exhibitors
- Visit the Naidex Village. Indulge in some retail therapy and take home lots of exciting, affordable products for you and your family
- Gain expert independent advice. Benefit from a free appointment with an OT, get advice from leading charities and find out about your entitlements
- Tour the Independent Living Show Home. Transform your home with the latest products and adaptations
- See the latest Wheelchair Accessible Vehicles. Meet Motability for advice on their scheme and explore the latest adapted vehicles
- Get free parking. If you're a Blue Badge holder, you can park next to the hall for easy access

**Saturday 27 October**

**Saturday 10 November**

**Saturday 24 November**

### **Berkhamsted Courthouse Christmas card sale**

We shall have a stall on each of the above dates, selling Christmas cards and small gifts. Please come along between 9.30 and 3.

### **Wednesday 5 December 7pm – Christmas Party**

Come and join us again at The Noke for some festive fun and mince pies. A chance also to buy those Christmas cards you may not have bought yet.

## **DONATIONS**

We received £627 from the Waitrose store in Rickmansworth, from their Waitrose Community Matters Campaign. If you have a Waitrose near you, you only have to fill in a form, and wait until we are chosen to be one of 3 charities selected each month. This is a very easy way to raise money and improve awareness to the general public.

**We would like to thank *everyone* who donates to the branch, as we could not help people living with MND without your generosity.**

## **FUNDRAISING**

### **Saturday 18 August Collection Outside Marks & Spencer Rickmansworth**

We had a sunny day and a reasonable turnout from the public. Our nine collectors raised £460 which was £16 down on last year. Thanks to you all.

Roland Lewis

## **HOWARD'S TANDEM SKYDIVE**

Howard Johnston is doing a sponsored tandem skydive on Sunday 7<sup>th</sup> October 2012 in aid of the South Herts Branch of the MND Association.

Howard is living with MND and is hoping to raise £1000.

For details on how to sponsor Howard, visit

[www.doitforcharity.com/HowardJ](http://www.doitforcharity.com/HowardJ)

## **'THE NEWS' from the MND Association ONLINE**

This publication is very useful and informative.

You can view the latest edition and archived electronic copies of The News at [www.mndassociation.org/thenews](http://www.mndassociation.org/thenews)

*US tourist to Irish child: "Does it ever stop raining here?" Child replies: "I don't know, I'm only eight."*

## AN EVENING TOUR OF TRING BREWERY

Our visit to Tring Brewery was an enjoyable and informative evening. We were able to sample all of their distinctive brews, though soft drinks were available for the non-drinkers. Ben, our tour guide was very knowledgeable (well he does work there) and described in great detail the complex brewing process. Beer has only four ingredients; hops, usually from Kent or Worcestershire, malted barley, locally sourced water and yeast. The yeast is specially cultivated, and is unique to Tring Brewery.



However, it is the way in which the ingredients are processed, heated, blended, cooled and fermented which define the unique Tring beer qualities.

Tring Brewery produce a 'permanent range' of beers, supplemented by a 'seasonal range' and 'monthly specials'. Beers are stocked locally, though are available for short periods at other Pubs as "guest beers".

The shop stock the current range of beers in addition to mustards, pickles, merchandise and an interesting chocolate and chilli bar. The visit raised £200 for the branch including the raffle. Rosemary Lingwood



## **ELINOR MUMFORD AV (ASSOCIATION VISITOR)**

I am proud to call myself a Yorkshire Lass, or even "The Lass of Richmond Hill" since I lived in Richmond, North Yorkshire until I went to Oxford to train as an Occupational Therapist. There I met my husband of 41 years, Michael. We have 2 children and two grandchildren.

My most recent job started in 1990 with social Services in Adult Care, covering the Harpenden and St Albans area. I loved the job and stayed until I retired in 2007.

Towards the end of my career I attended a training day held by Liz Garrod of the MND Association. Liz and I had been communicating extensively by email concerning a lady with MND that I was trying to organise a through ceiling lift for, so I felt I already knew her when we finally met. I told her I was due to retire and she said "You'd make a good Association Visitor". She had obviously got to know me too! I was selected and did my training in London in late 2007 and have been an AV ever since.

Many people do not know that AVs have to undergo training. It is two full days plus a residential weekend and it really makes you examine your attitudes and past experiences of life and life limiting illnesses. Many people who think they might like to be an AV get no further than the first day's training and even fully trained the drop out rate is quite high. We have to attend conferences and training days each year in order to retain our accreditation with the MNDA. Many AVs are ex professionals like me, others may have had personal experience of caring for someone with MND, either family or a friend. Others may never have come across MND before. One young man I did my training with had thought he was volunteering to work for the mental health charity MIND. Never the less he completed the training and made a good AV.

What does an AV do? Well obviously as the name suggests, we visit people with MND in their own homes or place of choice. But that is not the whole story. Our remit is to support plwMND (people living with MND), their carers and anyone

affected by MND in whatever way they feel would be helpful to them. The most important attribute an AV needs is a good pair of ears to listen. After that some reading between the lines may be necessary to tease out what is being said. That may be all that is necessary to make the plwMND or their carer feel better about what is happening in their lives. Everything told to us is in complete confidence unless we feel information needs to be shared with professionals involved in the case, for example. As a former OT I can read between the lines and refer people on to more appropriate sources of help, for instance if somebody tells me that they are losing weight and are having difficulty swallowing I know I need to refer to a dietitian for an assessment and possible referral for a PEG. I am often asked what to do in certain situations and frequently advise a phone call to MND Connect who are often the best people to respond to queries. AVs are very often a pointer to sources of information than the providers of information ourselves. As an AV I am allowed to refer to the Wheelchair Services and know the referral will be treated as urgent. In 2013, AVs are going to work in partnership with the Department of Works and Pensions when the new disability benefit for the 16 to 64 year age group comes in. This is an example of the necessity for AVs to keep up with training some of which can be very specialist.

All AVs will give the plwMND they are allocated to look after their contact details, either phone or email or both. We can be phoned theoretically at any time of day or night, but I have never been woken up myself. If I miss a call I get back to the caller as soon as I can. I will try and make contact by phone at least once a month, usually the week before the MDT (multidisciplinary team) meetings. If there is a problem I am often intensively involved for a while until the problem is resolved. In South Herts there is a MDT once a month which I make every effort to attend when professionals from Health and Social Care meet to discuss the cases of plwMND who have given their permission for us to do so. In this way the

plwMND has a rapid and co-ordinated response to any symptoms which may need further assessment and thus keep as high a standard of well being as possible.

So, in a nutshell, AVs could be described as "Hear all, see all and say nowt" (except with permission and in confidence). It is a very rewarding job, albeit voluntary. I hope I have made a difference to some people during a very stressful and distressing period of their lives.

Elinor Mumford

## **SKIN CELLS FROM MND PATIENT USED TO CREATE MOTOR NEURONES**

A breakthrough using cutting edge stem cell research could speed up the discovery of new treatments for MND. The international research team has created motor neurones using skin cells from a patient with an inherited form of MND.

The study discovered that abnormalities of a protein called TDP-43, implicated in more than 90 per cent of cases of MND, resulted in the death of motor neurone cells.

Professor Sidharthan Chandran, of the University of Edinburgh, said: "Using patient stem cells to model MND in a dish offers untold possibilities for how we study the cause of this terrible disease, as well as accelerating drug discovery by providing a cost-effective way to test many thousands of potential treatments."

Dr Brian Dickie, Director of Research Development at the MND Association, said: "This advance is a significant milestone on the road to developing a laboratory model of MND that faithfully reflects the cellular events happening in the patient. It is also a testament to the importance of international collaboration, with eminent scientists from leading institutions around the world focussed on the common goal of understanding and, ultimately, defeating this devastating disease". Mark Macan-Lind

## THE HARDEST HIT CAMPAIGN



Disabled people, those with long-term conditions and their families are being hit hard by cuts to the benefits and services they need to live their lives. The Hardest Hit campaign, organised jointly by the Disability Benefits Consortium (DBC) and the UK Disabled People's Council, brings together individuals and organisations to send a clear message to the Government: STOP THESE CUTS NOW

Facebook: [www.facebook.com/thehardesthit](http://www.facebook.com/thehardesthit)

Twitter: [www.twitter.com/hardesthit](http://www.twitter.com/hardesthit)

### **The Hardest Hit is back this October**

A major week of action is being planned for 20 – 28 October, with a report launch and events taking place across the country. To learn more about what is planned, go to

[thehardesthit.wordpress.com/](http://thehardesthit.wordpress.com/)

Now is a really important time, with a potential £10 billion of further cuts coming from the welfare budget by 2016. The Government is finalising plans for the new benefit Personal Independence Payment (PIP – the benefit replacing DLA), and crucial decisions on PIP and wider benefit changes through the new Universal Credit will be debated in Parliament in November.

## PARALYMPIC ROWING at ETON DORNEY

Dorney Lake is a modern world-class rowing and flat-water canoeing centre set in a spectacular 450-acre parkland near Windsor. The site was voted top Olympic venue hosting the Rowing and Kayak events during the Olympic and Paralympic Games for London 2012. It is owned by Eton College.



On a damp morning, we got up at 5.30am to drive to the Paralympic rowing at Eton Dorney. We had a very uneventful journey and despite not knowing the route, we got there 1 1/2 hours before the start. The roads and route were clearly marked and we had the use of an enormous car park with a large disabled vehicles section. After passing through ticket checking and security, I asked a pretty sergeant (female) what time she had got up and she replied 4.30! We had a 15 minute walk in my manual wheelchair on a smooth service to the grandstands. You could travel by buggy or an adapted vehicle but this would mean missing the dozens of happy smiley volunteers who really cheered us up despite the drizzle. On arrival, we found an access ramp which took us to the front of grandstand 1 where we found lots of room and a good view of the course. No cover unfortunately. We settled down to watch eight races but, disappointedly, the

first five did not feature TeamGB. In the next two races GB came fourth – so near and yet so far! Fortunately, in the last race – mixed cox four – we comfortably won by two seconds. We all stayed for the medal ceremony and roared our heads off when TeamGB paddled past our grandstand.

On our 15 minute walk/push back to the car park we were again greeted by the amazingly cheerful volunteers despite the drizzle. Getting out of the car park was a doddle and ten minutes later, we were on the M4 and soon home.

Roland Lewis

## **GREAT NEWS \*\*\*\*\*LOCALGIVING.COM ANNOUNCES £500,000 GROW YOUR TENNER CAMPAIGN**

In June we told you how you could make a donation, with Gift Aid, to the branch, via a new website called [Localgiving.com](http://Localgiving.com). From 25th September Localgiving.com will encourage new supporters to make one-time and/or ongoing monthly donations on the website by **matching up to £10 per donation**. They have got a pot of £500,000 to match donations, and will match up to £10 per donation until the pot is gone, raising awareness and funds for local charities and community groups across England.

**So when a supporter gives £10, they will double it to £20!  
And even better- when a supporter signs up to donate  
£10/month to a local charity, they will match the first three  
months!**

The new monthly donations feature will enable supporters to give automatically and regularly to local charities through online Direct Debit.

**So, there is no better time to make a donation !!!**

If you wish to donate in this way to the South Herts Branch of the MND Association, go to [localgiving.com](http://localgiving.com) and type **mnda** into the box top right, called **Search charities by keyword**

Thank you

## **PARALYMPICS OPENING CEREMONY WITH MNDA PATRON PROFESSOR STEPHEN HAWKING**

In September, science took pride of place alongside the athletes at the opening ceremony of the Paralympics. Under the guidance of the extraordinary [Stephen Hawking](#), Prospero took Miranda and the rest of us on a voyage of scientific discovery, celebrating the Enlightenment that brought rationality to unlock the secrets of nature and to advance the rights of man.

This wonderful ceremony highlighted the achievement of human will in overcoming the adversity of disability, and tackling the difficult problems of science. It also brought home to those of us who live on these "Isles of Wonder" that Britain was the birthplace of the Paralympics, and through the efforts of the Royal Society in the 17th century was also the birthplace of modern science.

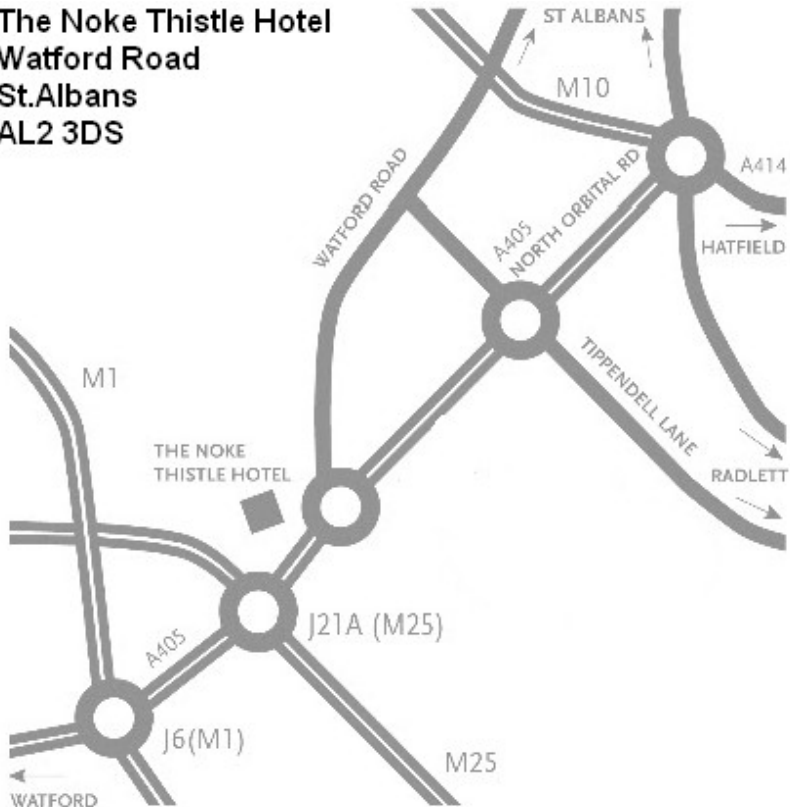
Science has done much to improve everyone's lives and has had a part to play in bringing us the great celebration of sport that happened in London this summer. Sir Ludwig Guttmann, the father of the Paralympic Games, a scientist and fellow of the Royal Society, was one of the first to recognise the important role sport can play in managing disability; science also underpins the medical and technological advances that help Paralympians in their athletics.

Involving Stephen Hawking in the opening ceremony celebrated science's equivalent of a Paralympian, a man who has not let disability stand in the way of great achievement. He emphasised the burning curiosity of scientists and the wonder of the science they do – how Newton could link the fall of an apple with the movement of the planets, uniting the local with the universal.

*I'm good friends with 25 letters of the alphabet ... I don't know why*

*I was watching the London Marathon and saw one runner dressed as a chicken and another runner dressed as an egg.  
I thought: 'This could be interesting'*

**The Noke Thistle Hotel**  
**Watford Road**  
**St.Albans**  
**AL2 3DS**



**THANKS TO THE NOKE THISTLE HOTEL**

We are extremely grateful to Simon Thatcher, the General Manager of The Noke Thistle Hotel in St. Albans, who has generously agreed to continue to allow us to use the hotel for our meetings.