

South Herts Branch DECEMBER 2012 NEWSLETTER



Sally Light, who has just been appointed The Chief Executive of The MND Association. See article inside.



Patron - Dr Carol Scholes

Macmillan Consultant in Palliative Medicine in the Community

Committee Members

Lesley Ralston	Chair	01923 778 990
Jennifer Hay	Vice Chair	01923 720 198
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Roland Lewis	Newsletter Editor	01923 720 198
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MND
connect
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CHAIR'S REPORT DECEMBER 2012

I can't believe Christmas is nearly here – again!

We have had a good year with some nice events, such as the performance of Loot which was a sell out, and very funny. A visit to the Tring Brewery, where a good time was had by all – with a tour of the brewery and tasting of their specialist beers! There was also our nomination at the Mayor of St Albans Pride Awards.

Our (not so new now) Carers Club is a great success and has a stalwart following. We have a good chat and a laugh. As I have said before, we are all carers or were carers and although we have that in common, we by no means allow that to dominate our meetings. However, if you would like to talk about anything privately with one of us, we would be delighted to help in any way we can. Liz Garrod, the neurological co-ordinator for Herts, sometimes attends and she is a fount of knowledge, as well as lovely to talk to. All are welcome and, please, ring me if you would like a chat before coming – these things can feel a bit intimidating before you do them. My number is 01923 778990.

I would also like to say that if you would like to come to any of our meetings please get in touch if you have transport problems – we would be happy to help to fund a taxi there and back. Please don't be shy – that's what we're here for.

One of the things which as a branch we try to do, is raise the profile of this horrible disease to the wider public – which is not very easy. Due to set of coincidences I managed to be interviewed by Nick Coffey one of the DJ's on 3 Counties Radio = not once, but 3 times. The first time was to tell my story as a carer. He was charming and made me feel completely at ease. It's so difficult to be able to arrange these things – getting in touch is never easy, especially with the press, people leave or are not there and that's that. We could really do with someone on our committee (or not!) who would help with publicity and public relations. The biggest problem is that we are competing with so many other charities. The big

ones have all the advantages – money, paid staff and they are the ones which are uppermost in the public's minds.

On the subject of volunteers, we've had some success this year with 2 new volunteers on the committee, both very proactive and enthusiastic. Peter Bayley (who has a scientific background) is our new secretary. Sian Goodwin who worked in the NHS all her life (that's a definite advantage!) has joined the committee. When our long standing treasurer unfortunately resigned it could have been disastrous. But magically someone got in touch just at that point and (a 3rd) Alison Murdoch stepped into the breach.

It gives us all so much optimism when things work out like that.

We are enclosing with the newsletter, a Christmas Appeal form. We now have our Co-Ordinator of Care for people with Neurological Diseases and our help is being called upon more frequently now that Liz Garrod is helping so many people with MND. That is what we want to happen, but in the present economic climate businesses and sponsors are hard to find and the donations we used to receive just aren't happening. I do hope you will give generously and support the South Herts Branch. It doesn't have to be a big amount – every little helps!

On the subject of fundraising, all the supermarkets now have charity donation boxes in-store, and give you the opportunity of donating, by putting a token in the box to support your favourite local charity (or a similar scheme). They donate an amount of money in proportion to the support each charity has received. We were lucky enough to be in the Waitrose store in Rickmansworth and we received the lion's share! We're also in John Lewis in Watford NOW. PLEASE support us. You can pick up a form in-store and apply for South Herts Branch of the Motor Neurone Disease Association to be one of those lucky charities. If you need any help filling in the form, please get in touch with me on 01923 778990.

We'd love to see you at the Christmas party on

Wednesday 5th December 7pm at The Noke – there'll be mince pies and festive drinks, a quiz, a raffle and MND Christmas cards and gifts for last minute shopping.

Next year we have our AGM on Wednesday 3rd April, as usual at the Noke Hotel, St Albans. I must say a word about The Noke. They have been so generous to us now for over 3 years, allowing us to use the hotel for all the meetings which we request. The Noke is a lovely hotel, very efficient and beautifully presented and the staff are exemplary and very friendly. We are very lucky to have such a wonderful venue and I can't thank the Manager, Simon Thatcher, enough for his generosity. (Sunday lunch there is delicious!)

Having said all that, I have got through this year on a wing and a prayer! What with moving twice which was very stressful as I was downsizing after 25 years. (I had to go into a rented house for 3 months, which was horrible). Then unfortunately the move practically coincided with several weeks holiday in Canada where one of my sons lives. However, I love my new (new) house and am slowly getting settled and organized. Holly, my dog, is also beginning to feel safe again. Next year I'm back with my finger on the pulse and hope that South Herts Branch carries on its success and has lots of luck – which is how so many good things seem to happen.

So all that remains is for me to wish you a good Christmas and Happy New Year!

Lesley Ralston x

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

FUTURE EVENTS

Wednesday November 28 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 dates for carers meeting, all at 11am.

Wednesday 16 January

Wednesday 20 March

Wednesday 15 May

Wednesday 17 July

Wednesday 18 September

Wednesday 20 November

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

Some of the donations we have recently received are,
£20 from Anna and Nick Smith
£200 from John Barton and a regular lady donor from Hatfield
£135 from Mr Latimer's neighbours
£485 in memoriam for Jean Latimer
£200 from Bill Waite
£25 from Yianni Charalambous

FUNDRAISING

Thanks to Colin, we already have some collection dates for next year.

St Albans, 18 May 2013

Harpenden, 20 July 2013

Welwyn Garden City, 23 November 2013

If you can help, for just 1 or 2 hours, in any of these towns, please contact Colin. **We really need your help.**

ADVANCE MAY LEAD TO NEW TREATMENT IDEAS

Scientists at the University of Bath are one step further to understanding the role of one of the proteins that causes MND. Published in the prestigious journal Nature Communications and funded by the Wellcome Trust, University of Bath researchers looked closely at the structure of 11 mutated angiogenin proteins, and how changes in their structure influenced activity, function and survival in motor neurones. Dr Brian Dickie, our Director of Research Development, said: "The researchers at the University of Bath have skilfully combined aspects of biology, chemistry and physics to answer some fundamental questions on how angiogenin can damage motor neurones. It not only advances our understanding of the disease, but may also give rise to new ideas on treatment development."

Read more about this and other research news on our research blog <http://mndresearch.wordpress.com>

The News October 2012

HOWARD'S TANDEM SKYDIVE



Howard Johnston has completed his sponsored tandem skydive in aid of the South Herts Branch of the MND Association. He says:-

“My OT had suggested making a list of things I wanted to do whether my condition permitted it or not and then to find out if it would be possible! Top of the list was Sky diving. I really didn't believe I would be allowed to do it as I have difficulty lifting my legs up but two months later, there I was sitting on the edge of the planes doorway at 10,000 feet. Well it wasn't scary as the ground looked unreal but gosh it was cold on my face travelling at 120 miles per hour. 40 seconds later, I felt the jerk as the parachute opened and we started going down gently. It was so relaxing and it wasn't until we got a few seconds from landing that you realise how fast you are going. My tandem guy (Dave) gave us a very gentle landing sliding in on our bottoms. Great fun and the first thing off my bucket list. I would recommend it to everyone and to top it all, I raised money for the MND Association”. Donations can still be made at www.doitforcharity.com/HowardJ

*****STOP PRESS*****

Howard has raised £1,188.75 to date, so well done !

To see a video of the jump, go to

<http://www.youtube.com/watch?v=ObckPy5Lkh8&feature=plcp>

THE RESPITE ASSOCIATION

When you are caring for someone the task can be overwhelming. You can be on 'duty' for 24 hours a day for seven days a week with no breaks or holidays. This is too much to ask of anyone.

We provide short term assistance in the funding of appropriately qualified respite care for disabled, sick, elderly or terminally ill persons in order that their regular carer can be allowed to take a much needed break.

Many of the people who are at home caring for loved ones are forced to live on very limited incomes. It is these people that we are working to help.

Whilst providing suitably qualified carers in the home or funding a temporary place in a residential care centre can be expensive, the benefits to the carer are beyond measure. The cost and level of support varies dramatically from a few pounds to several hundred with an average level of around £400.

www.respiteassociation.org

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What do you call Santa's helpers? Subordinate Clauses

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'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

BERKHAMSTED BOOKWORMS LADIES SUPPER

In 2010, Ruth, a member of our book group passed away after suffering from MND. We felt we wanted to raise some money in her memory. Last year we held a Boden clothes party and gave the commission on sales and donations for coffee and cakes to MND.

This year we organised a “Ladies Supper” held on Friday 12 October. We transformed Carolyn’s house into a very smart restaurant for the evening and 21 glamorous guests enjoyed canapés followed by homemade meat or veggie lasagne and salad and finishing with a choice of five tempting desserts, coffee and delicious chocolate fudge.

Guests and cooks all had tremendous fun and thanks to the generosity of our guests and some unable to attend we raised £385 for MND



Sue Atkinson

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What did the bald man say when he got a comb for Christmas
“Thanks, I’ll never part with it”

NEW CHIEF EXECUTIVE APPOINTED

The Motor Neurone Disease Association has appointed Sally Light as its new Chief Executive.

Sally, who joins the MND Association in December, is currently Director of Rehabilitation at the Royal Hospital for Neuro-disability and has considerable experience of leadership and management within the NHS and health services.

She joins the Association following the departure earlier this year of Dr Kirstine Knox, who had been Chief Executive since 2005. Kirstine left the Association in April after her husband became seriously ill.

Mark Todd, Chair of Board of Trustees, said: "The Board is delighted to have secured Sally, whose leadership and knowledge will guide us through the considerable ongoing change within the external environment and ensure we continue to make the biggest possible difference for people with MND.

Sally said: "I am delighted to be joining the MND Association, an organisation which makes a significant difference to the lives of people living with motor neurone disease. I am joining at an exciting and challenging time and look forward to working with the Board, staff and volunteers to build on the Association's excellent progress to date."

Mark Todd added: "I would like to take this opportunity to thank Alasdair McLeish, our Director of Finance, for taking the reins as Acting Chief Executive during the absence and following the subsequent departure of Kirstine Knox."

FLU INNOCULATION

The Department of Health advises that people living with chronic diseases, including Motor Neurone Disease (MND) should get the flu jab if it has not already been offered to them. People living with MND are seen as an 'at-risk' group who should have the vaccination each winter.

RESEARCH NEWS FROM THE MNDA

Encouraging NP001 clinical trial results for MND.

Promising results from a Phase II clinical trial for a drug called NP001 have been announced by the biopharmaceutical company Neuraltus.

The trial, conducted in America, suggested that NP001 is safe, well tolerated and could be beneficial for MND. Following these encouraging results, Neuraltus plan to begin a larger, Phase III trial of NP001 in the second half of 2013.

The trial

The Phase II clinical trial for NP001 was rigorously controlled. This means that it was randomised, double-blinded and placebo controlled. These are important factors in controlling possible bias. The trial included 136 people living with MND in America across multiple centres. Participants were randomised into three groups to receive an intravenous infusion of either high dose NP001, low dose NP001 or placebo (inactive substance) treatment for six months. They were then followed for an additional six months. Approximately 45 people were used in each treatment arm.

The results

Results suggest that the treatment was safe and well tolerated. Promising signs of effectiveness were also identified, but were not statistically significant to draw firm conclusions as to whether the treatment could be effective for MND.

The trial organisers state in their press release that 27% of people taking the high-dose NP001 did not progress during the trial period. It's important to treat these results with a certain degree of caution, as approximately 10% of people taking the inactive placebo also did not progress during the same period as measured by changes in the functional rating scale.

The results provide enough evidence to warrant a larger scale trial to investigate this treatment further.

This finding also importantly identifies the optimum dose that

should be used in this larger-scale clinical trial, as their results suggest that a higher dose could be more likely to yield a beneficial effect than the lower dose. Finding out the optimal dose is an important part of Phase II clinical trials to 'fine tune' the details to provide the treatment with the best chances of demonstrating its success at Phase III.

Importance of sharing results via peer-review

These results will need to be published in a peer-reviewed scientific journal. Peer review is an important process to determine whether findings are valid and that appropriate standards have been used in the study. Once published, these findings will also be used by the scientific community to add to their knowledge.

Importance of Phase III planned for 2013

The promising results identified in Phase II will need to be confirmed in the Phase III trial planned for the second half of 2013. Leading UK clinical trial researcher, Prof Nigel Leigh said, "A larger Phase III randomised placebo-controlled trial is required before we can be confident that these positive trends are consistent and clinically significant."

Dr Brian Dickie, the MND Association's Director of Research continues, "We welcome Neuraltus' plan to initiate a Phase III trial to determine whether NP001 is beneficial for people living with MND."

WWW.HEALTHTALKONLINE.ORG

People's stories: see, hear and read their experiences...

Healthtalkonline is the award-winning website of the DIPEX charity. Healthtalkonline and its sister website, Youthhealthtalk, let you share in more than 2,000 people's experiences of over 60 health-related conditions and illnesses. You can watch video or listen to audio clips of the interviews, read about people's experiences if you prefer and find reliable information about specific conditions, treatment choices and support.

The information on Healthtalkonline relies on external funding

and is based on qualitative research into health experiences, led by experts at the University of Oxford. These personal stories of health and illness will enable patients, families, carers and healthcare professionals to benefit from the experiences of others.

Getting started

To get a feeling for what's on the site, click on a category that interests you on the home page, such as "Heart Disease". Then you'll see the types of heart disease we've covered so far. Click on whichever interests you, say, "High Blood Pressure". You can then choose to browse through "People's stories" or click on a popular topic to see what our interviewees had to say about it.

Or you may want to watch the introductory video by broadcaster Jon Snow. Click on his picture on the right side of the home page.

All pages other than the home page have a similar arrangement. Most pages start with an explanation of what you'll find there. On the left and top of each page, you can click through back and forth between sections. You can return to the home page by clicking on the word "home" at the top of each page.

Feel free to explore the vast range of stories and information – there's a wealth of experience and information here. See below for my interview.

www.healthtalkonline.org/Nerves_and_brain/motorneuronedisease/People/Interview/1690/Category/348/Clip/12517/

Roland Lewis

BRANCH PATRON

We are thrilled to report that, after three years as our Branch Patron, Dr Carol Scholes, Macmillan Consultant in Palliative Care in the Community has agreed to continue for a further three. She brings a high profile and support to the branch, for which we thank her very much.

AGM and ANNUAL CONFERENCE 2012

The MND Association's 27th Annual General Meeting (AGM) and Annual Conference took place on Saturday 15 September, at the Radisson Blu Hotel, Stansted Airport. The day brought together 169 delegates, 35 of whom were people living with MND.

The Association's Chair of the Board of Trustees, Mark Todd, said: *"Even in the midst of difficult challenges and decisions, one of the joys during this time has been talking to volunteers and members about the goals we share."*

Following on from the formalities of the AGM in the morning, the afternoon's Annual Conference, included a presentation by the Association's Director of Research, Dr Brian Dickie and Dr Chris McDermott from the Sheffield MND Care Centre.

Dr McDermott talked about how a lack of evidence in many areas of clinical treatment of MND means clinicians tend to rely on their own experience when treating patients. He highlighted the need for an evidence base that would inform decisions between people with MND and their physicians on how best to manage their care.

Election results for the Association's Board of Trustees were announced, with the successful re-election of Alun Owen and Juliet Draper and the newly elected Trustee Mark Stone.

We also thanked Jean Waters for her valuable contribution to the Association, as she stood down from the Board after two three-year terms as a trustee, including two years as Vice Chair. Jean, who received a framed certificate and flowers said: *"It has been an honour to be a trustee – thank you."*

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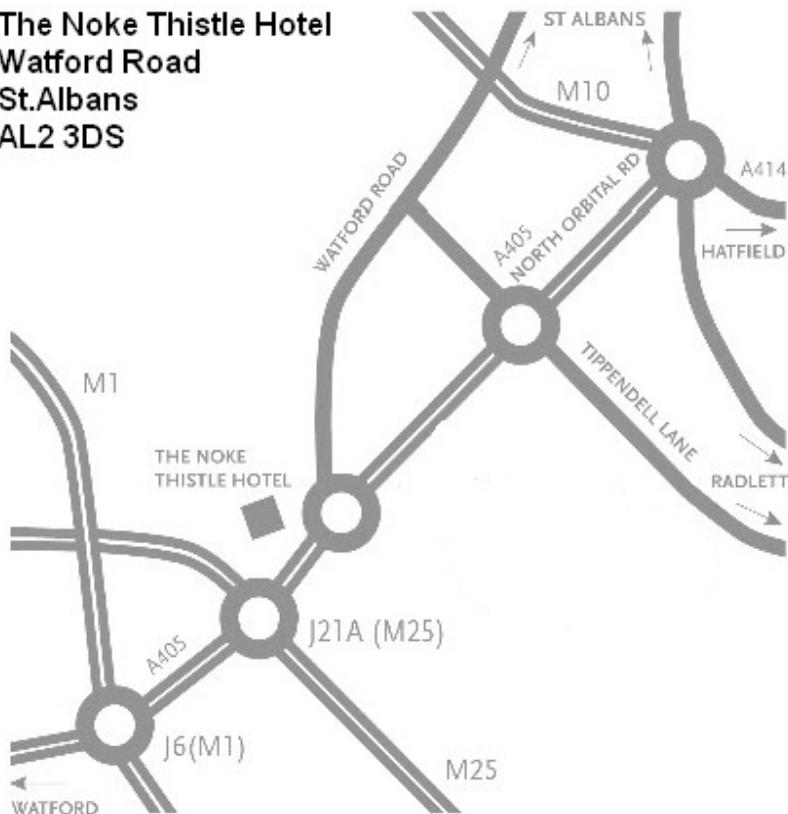
What did Adam say on the day before Christmas ?

"It's Christmas, Eve"

Why didn't the skeleton go to the Christmas party ?

He had nobody to go with.

**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.