

South Herts Branch

FEBRUARY 2013 NEWSLETTER



MND Connect is the National Office Helpline

mndconnect@mndassociation.org

www.mndassociation.org

Motor Neurone Disease Association – Registered Charity No. 294354

MND
connect
08457 626262

Patron - Dr Carol Scholes

Macmillan Consultant in Palliative Medicine in the Community
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KEY FACTS ABOUT OUR BRANCH OF THE MND

The South Herts branch of the MND Association is totally run by volunteers.

The branch looks after people within the postcodes AL, WD, EN6 and HP 1,2,3,4 and 23.

The branch donates money towards research, and the rest is spent locally, supporting people affected by MND with special equipment, financial support etc.

DONATIONS

To make a donation to the branch please make cheques payable to; “**MND Association South Herts Branch**” and send to Alison Murdoch, 41 Orpington Road, Winchmore Hill London N21 3PL

OR

go to Localgiving.com, type **mnda** into the box top right, called **Search charities by name** and make a payment to the South Herts Branch of the MND Association, which can include an automatic gift aid reclaim.

CHAIR'S REPORT FEBRUARY 2013

I wish you good things in 2013.

I'm sitting here typing and looking out at lovely white pristine snow. (That means that the council haven't cleared the roads!!) But I am being kept very amused and busy, as I took possession of two kittens on Thursday. They are tabbies and called Kitty and Puss. They are running rings round me! Very sweet, and as they are 7 months old they are house trained and very well behaved.

I have a good feeling about the branch in 2013. We had a wonderful response to our Christmas appeal – thank you to all who responded.

We were also chosen (again) by Waitrose in Rickmansworth as their December charity – that is an unprecedented twice in one year. And also by John Lewis in Watford as their charity for the final quarter of 2012.

PLEASE look out for forms in all the supermarkets now, to apply for South Herts Branch to be in their charity collections. If you need an idea of what to put on the form, see the example on the next page. It is a bit tricky, as you think, "haven't I just answered that question in the previous bit." Takes a bit of thinking about!

We had a planning meeting earlier this month and if all works out, we hope to have a barn dance and a quiz night in the spring and autumn. We already, of course, have our Carers Club coffee mornings, but we would like to start having drop ins around lunch time for people with MND, and their friends and family. We are investigating pubs in the St Albans area as that is so central to our patch. I emphasize how informal and friendly these are – you can come when you feel like it, there is no agenda, just chat and a light lunch which we will provide.

Anyone who would like help with transport to any of our meetings – please let us know and we would be happy to help to arrange, if necessary, and to pay, if you need a taxi.

It will be time for the AGM again on 3rd April. It will as usual be held at the Noke Hotel in St Albans at 7pm. We hope that Liz Garrod, our Co-Ordinator of care for people with neurological conditions in Hertfordshire will be coming to talk to us. Liz is well loved by so many of us and has helped so many people with MND and their carers and families. She was our Regional Care Development Advisor, working for the Motor Neurone Disease Association, when my husband Derek had MND back in 2007.

At present we are all waiting with bated breath to see if Liz gets funded to continue the job. It will be a huge loss to us if she does not. If anyone would like to know who to write to about this, please let me know and I will send you the information.

I do hope you will come to the AGM (which could not be more informal and is usually quite chaotic!) so we can all catch up and it is a lovely occasion to make new friends.

Lesley

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

SAMPLE OF WAITROSE APPLICATION FORM .

Do you know a local cause that you would like to support through Community Matters?

I think SOUTH HERTS
BRANCH OF THE MOTOR
NEURONE DISEASE
ASSOCIATION Contact details of nominated
cause (if known)

deserves support from
Community Matters because
WE HELP FINANCIALLY AND
SUPPORT PEOPLE WITH MND.
A TERMINAL NEUROLOGICAL
DISEASE. THERE IS NO
TREATMENT AND NO CURE Please hand in the completed
form at the Welcome Desk.

Thank you for your nomination. The good cause you have nominated will be contacted if successful.

(YOU CAN PUT YOUR CONTACT DETAILS -OR MINE
IF YOU WOULD PREFER : Lesley Ralston, Chair,
South Herts Branch - 01923 778990.

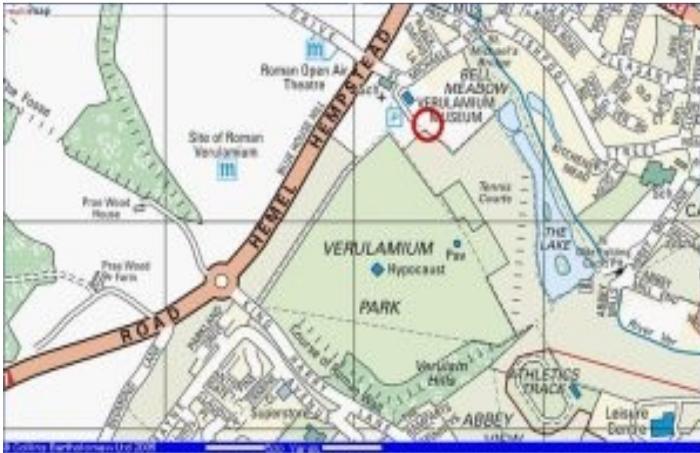


FUTURE EVENTS

Wednesday 20 March 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 20 March

Wednesday 15 May

Wednesday 17 July

Wednesday 18 September

Wednesday 20 November

SPRING CONFERENCES

THE dates and venues for the Association's 2013 Spring Conferences have been confirmed as follows:

- 🕒 Saturday 13 April , The Cambridge Belfry, Cambridge
- 🕒 Sunday 14 April, Ashford International Hotel, Kent
- 🕒 Saturday 11 May, The Majestic Hotel, Harrogate
- 🕒 Sunday 12 May, De Vere Village Heron's Reach, Blackpool
- 🕒 Sunday 19 May, The Cheltenham Chase Hotel, Gloucestershire.

The programme and registration form will sent out with the winter Thumb Print, or go to www.mndassociation.org/news-and-events/events/conferences/spring-conferences

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,

In Memoriam Mr AL £842

Berkhamstead Bookworms £385

C M C £50

Hemmens Financial £100

Christmas Newsletter Appeal £855

Caged Bird Society £1,100

The Chalkdrawers Arms, Colney Heath £103.50

FUNDRAISING

Welwyn Garden City Collection, 17 November 2012

November 17 in Welwyn Garden City was a very quiet day.

There were very few people in the city, although those who were, did willingly donate many small sums and we raised £233.49.

Colin Gulliver

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

Berkhamsted 11 May 2013

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.**

MORE MONEY IN YOUR POCKET by AGE UK

Age UK have a useful leaflet on claiming benefits.

This can be downloaded from

www.ageuk.org.uk/money-matters/claiming-benefits/

Or by phoning 0800 169 6565

SOUTH HERTS BRANCH CHRISTMAS PARTY



Fiona, Lesley and Liz

The annual Christmas party on 5th December brought together more than 20 participants, a number somewhat limited by the onset of cold weather and the arrival of the season of colds and worse ailments.

Lesley started by thanking Caroline Snook, who has been an Association Visitor for over 5 years, and is retiring. She has been a cheerful member of our branch and a most appreciated AV.

Our two main guests were our speaker – Liz Garrod who is the Co-ordinator and Project Lead for Rare and Rapidly Progressive Neurological Conditions and Fiona Dowling, Senior & Advanced Speech and Language Therapist in Hertfordshire. Lesley explained that Liz has responsibility for co-ordinating the care and services applicable to these rare neurological conditions for the whole of Hertfordshire and works very closely with Fiona and other healthcare professionals.

South Herts branch raised £17,000 – from Veolia Water and The Northwood Townswomens Guild for equipment to be used

by Liz in her role. A cheque was presented to Liz and Fiona which they intend to use to buy 2 iPads + all the additional equipment for them, such as bags, insurance, cleaning, extra bits and pieces, etc. to enable people with speech problems to communicate. Hundreds of other 'applications' can be used by an iPad so it is a hugely beneficial aid.

Lesley also spoke about the possibility that Liz may not receive the funding to continue in her role as co-ordinator, when the present funding runs out. The absence of that role will be devastating for Hertfordshire and these neurological patients.

One aspect of the absence of a co-ordinator is that before we had one, many OT's and healthcare people would go the extra mile to help and therefore had the knowledge and contacts to do so. Most of those NHS employees have now gone and it will take years to build up such a back up system again. If anyone would like to write to the powers that be on this subject, please get in touch with me on 01923 778990.

We enjoyed mince pies and wine and were treated – or subjected! – to a stringent test of memory and general knowledge by John Barton once again. With the help of a little discreet eavesdropping some remarkably high scores were registered! John had also brought some raffle prizes and Colin Gulliver, once again did a splendid job of organising the raffle. Once again our thanks go to The Noke Hotel and the manager, Simon Thatcher, for their efficiency and hospitality for allowing us have the party and during the past year.

Peter Bayley

*My daughter asked me for a pet spider for her birthday,
so I went to our local pet shop and they were £70!
"Blow this," I thought, "I can get one cheaper off the web."*

Statistically, 6 out of 7 dwarves are not happy.

ASSOCIATION VISITOR CAROLINE RETIRES



Caroline was an Association Visitor (AV) for over 5 years and recently received a certificate to commemorate this achievement.

Caroline has now decided to resign primarily because she and her husband have bought a motor home and now plan to take frequent long holidays.

About 7 years ago Caroline decided to take early retirement from the Civil Service and looked for something to occupy her retirement. First of all she volunteered in the Care Office in Redbourn, where she lives, and also helped to transport the elderly to the Local Day Centre.

She received an email from the St. Albans Volunteer Bureau asking her if she would be interested in becoming an Association Visitor for the South Herts Branch of the MNDA. This interested her because she had previously lived in Surrey, where she used to visit patients in a long term care ward, and had a very special relationship with a particular patient who had MS

Once she was accepted Caroline carried out her intensive training course at Birmingham. She then joined the South Herts Branch only to discover that there was only one other AV working for the Branch ! Since then several more have been trained - *but we are always looking for more visitors.*

Caroline has visited many clients in her role as an AV and has always been amazed at how cheerful people have been on her visits and how very grateful they have been.

During her time as an AV, Caroline has regularly attended training courses and conferences, which is an ongoing requisite to practise as an AV. She always found them interesting and educational, but never ceased to be amazed by the medical advances being made by such clever doctors involved in research.

She also attended monthly Palliative Care meetings. Most attendees at these meetings are from various aspects of the medical profession and so it was a great privilege for her to be included, and be allowed to speak about her clients, with their permission of course.

She also attended local committee meetings where she became involved with fundraising. Caroline's family became involved and her son Edward raised over £1,000 when riding his bicycle from Redbourn to Great Yarmouth, with the support from his sister Jacqui.

Her dog Hubie also helped to raise money for the MNDA.

She enjoyed the five years she was an AV for the MNDA.

We will all miss you Caroline and thank you for your five years of care and commitment to the MNDA and wish you the very best of luck in all your new ventures.

Jenny Fellas, Branch Association Visitor

The wife has been missing a week now. Police said to prepare for the worst.

So, I have been to the charity shop to get her clothes back.

Borrow money from a pessimist -- they don't expect it back.

THE FISHERMAN'S FRIENDS



The Fisherman's Friends are shanty singers from Port Isaac on Cornwall's rugged, panoramic north coast, who have delighted visitors and locals there for more than 15 years.

Down on the harbour front of the tiny fishing village of Port Isaac, the authentic sound of the shanty can be heard loud and clear via the mighty, brawny chorale of The Fisherman's Friends. At around eight in the evening during the summer months, tourists and locals gather to hear this ten-man group mesh their voices in an incredibly rousing and joyful set of shanties and Cornish folk songs.

There's no gang leader, no choir master and no holds barred in the singing of The Fisherman's Friends. And fisherman's friends they truly are – each and every member of this unique group are or have been fishermen, lifeboatmen and coastguards (as well as builders, artisans, hoteliers, and shop keepers) in Port Isaac. They've known each other since childhood and learnt their powerful brand of Cornish harmony singing at the local Methodist chapel – now the pottery of

Fisherman's Friend Billy Hawkwins (baritone), where the group get together with a crate of ale and a good deal of bonhomie to rehearse their repertoire and try out new songs.

Their regular portside concerts have become a much-loved local institution and visiting celebs such as Chris Evans, Gloria Hunniford, Laurence Llewelyn-Bowen, have fallen under the spell of their Shanty singing. Their new album, recorded in a 15th-century church in nearby St Kew, features a rich haul of 12 songs from their Port Isaac repertoire, including the classic South Australia, the haunting Cornish robber ballad The Cadgwith Anthem and the beautiful Brightly Beams, their mesh of Chapel-inspired harmonies rising out of a big-band folk setting.

"We have a very full sound," says Jon Cleave (bass). "You've got the different grades of baritone in the middle, which all blend, and then there are the tenor harmonies at the top and I do the bass underneath – so it makes a fat sound, a full sound, a solid wall of sound. Like Phil Spector."

At their regular Port Isaac summer sessions, they stand in a line and each leads a song, from one end of the line and back again, giving them a huge variety of sound and song, and drawing from a repertoire of songs and shanties not only from Cornwall but Liverpool, Ireland, Africa, the West Indian, and America.

That sound has graced not only the Port Isaac, but the Royal Albert Hall and the BBC Folk Awards, where their harmony singing greeted guests in the foyer.

English folk music has enjoyed a renaissance in the last decade, especially in the west country, with the likes of Seth Lakeman, Jackie Oates and Show of Hands achieving widespread acclaim. Now, with their new album of favourite

Shanties due for release on April 26, The Fisherman's Friends have landed themselves quite a catch.

They performed at the St Albans Arena last year and will return on **Friday 8th February 2013**. It was one of the best shows I have ever seen. Catch them if you can.

www.fishermansfriendsportisaac.co.uk

Roland Lewis

23rd INTERNATIONAL SYMPOSIUM ON ALS/MND

Each year the Research Development Team, at the MND Association, proudly organise the International Symposium on ALS/MND, and this year was a record breaker! The symposium was held in Chicago where over 900 clinicians, scientists and healthcare professionals attended the three-day event. With 86 international speakers and over 300 posters they managed to write about it all in just over 5,000 words in daily articles in their blog.

To read all about it go to

www.mndassociation.org/research//International+Symposium

ARE YOU A CARER?

If you've spent time taking care of someone else, we can help you take a little time for yourself.

Carers learning and work service is a new, specialist and FREE SERVICE provided by Hertfordshire County Council and Herts Careers Services.

You can take advantage of this FREE SERVICE, if you:

- Live in Hertfordshire
- Are currently a carer, or have been in the past
- Want to get back in to work or study, or
- Want a career change if you are already working

Find out more by calling FREE (from a landline) on
0800 587 4103 and ask for the carers service

or email info@hcs.co.uk

DISABILITY LIVING ALLOWANCE (DLA) TO BE REPLACED BY PERSONAL INDEPENDENCE PAYMENT (PIP)

From 8 April 2013, the Government is introducing a new benefit called Personal Independence Payment (PIP) to replace Disability Living Allowance (DLA) for eligible working age people aged 16 to 64.

What the change means

Disability Living Allowance will end for everyone of working age even if they have an indefinite period award. By working age we mean everyone who is aged 16 to 64 on the day Personal Independence Payment is introduced.

There are no current plans to replace Disability Living Allowance for children under 16 and people aged 65 and over who are already receiving Disability Living Allowance.

Personal Independence Payment is based on an assessment of individual need. The new assessment will focus on an individual's ability to carry out a range of key activities necessary to everyday life. Information will be gathered from the individual, as well as healthcare and other professionals who work with and support them. Most people will also be asked to a face to face consultation with a trained independent assessor as part of the claim process.

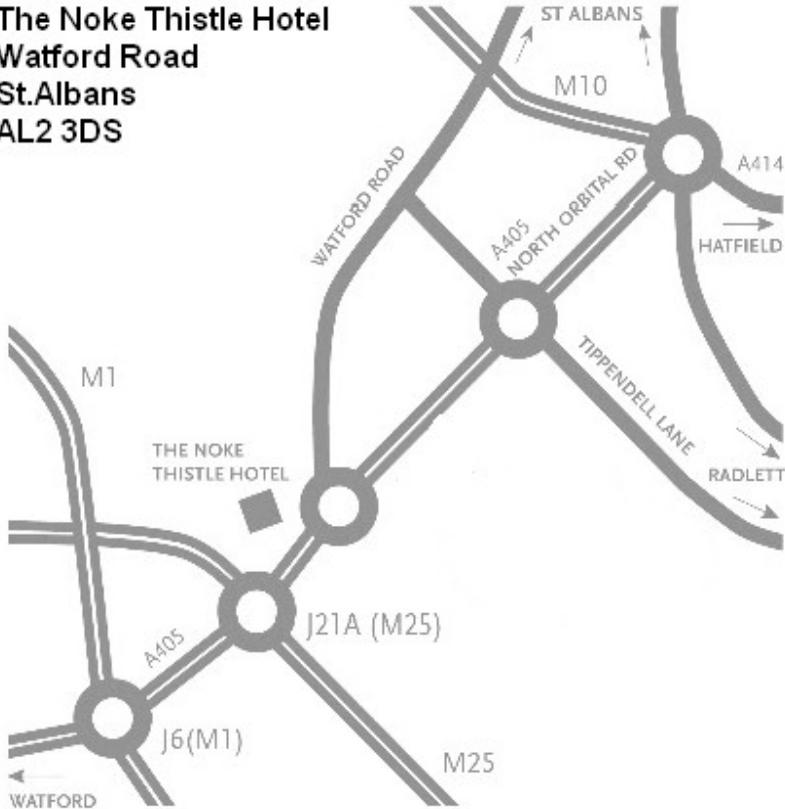
For more information, see www.dwp.gov.uk/pip

'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

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.