

South Herts Branch OCTOBER 2013 NEWSLETTER



Presentation of prizes for Christmas card competition.
From the left, Alexandra, Zoe (winner), the Mayor of St Albans, and Jack.

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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| | | |
|-------------------|--|----------------------------|
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KEY FACTS ABOUT OUR BRANCH OF THE MNDA

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

The branch looks after people within the postcodes - AL (except AL6, AL7, AL8), 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.

OUR BRANCH WEBSITE

www.mndasouthherts.org

'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

CHAIR'S REPORT OCTOBER 2013

Hello to everyone,

I hope your summer was enjoyable – it was sometimes a bit too hot for me but shouldn't complain as it was lovely to have a summer at all!

We were very disappointed to have to cancel the barn dance which was planned for 21st September due to the fact that we didn't sell enough tickets to make it viable. But as many people have said that they would like to come to a barn dance, we hope to try again next year, earlier in the year. We think it may have been that people have had their holidays and children (not to mention new university students) are going back to school.

If you have any views on these sort of events and when they should be held, please email (leshenhouse@gmail.com) or phone me on 01923 778990. We would be interested to hear of any things you would be interested in doing. If you know of any nice venues we'd be delighted to hear from you.

We are holding a lunch on Wednesday 2nd October at the Noke Hotel between 12 – 2pm. We would particularly like to invite anyone with MND and their carer or family member and would like to invite you as our guest. It will be very informal and we have Anne Walkington, who for many years was in charge of costumes at The Abbey Theatre in St Albans, coming to tell us all about that. If you would like to come please contact Peter Bayley (01582 713070).

Our lovely branch Christmas card designed by 10 year old Zoe has now been printed and is on sale and I tell you the story behind it later in the newsletter. I do hope you will support us by buying them.

We're also attending Christmas card sales where we'll be

selling those cards and also the MNDA Christmas cards. See dates in Future Events.

I've been invited to talk to the congregation of St John's Church in Harpenden and also at a ball being held in memory of someone who died recently. I will tell them about MND, the MNDA and our branch. I am delighted to do these talks as it is a brilliant way of raising the profile of MND locally, gives an opportunity to ask for new volunteers, and is often a source of fundraising.

If anyone would like to suggest another possible opportunity to do this, please let me know and I would be more than happy to do so.

We are always looking for new volunteers – to join our committee or just to help our street collection team for a couple of hours, now and then.

If anyone has a child or grandchild who is an expert in social media (aren't they all !), we are desperate to find someone to get us involved in that. They would have to be prepared to take it over for us as we are all old fogies on the committee and completely baffled by it ! It would be invaluable to us if we could get into social media – many other branches already have.

I shall be attending the (Iain) Rennie Grove Hospice Care Annual Conference on 16th October where there will be some excellent speakers, including our own Liz Garrod in her capacity as Co-Ordinator and Project Lead for Rare and Rapidly Progressive Neurological Diseases. (Shouldn't really call her 'our', but can't resist it).

I'm off to my beloved Cornwall in November, with my new little Jack Russell/Norfolk Terrier cross puppy, Bella – who is

running rings around me and would happily go off with everyone she meets.

I do hope you will be able to come to our Christmas party on Wednesday 4th December – all are welcome.

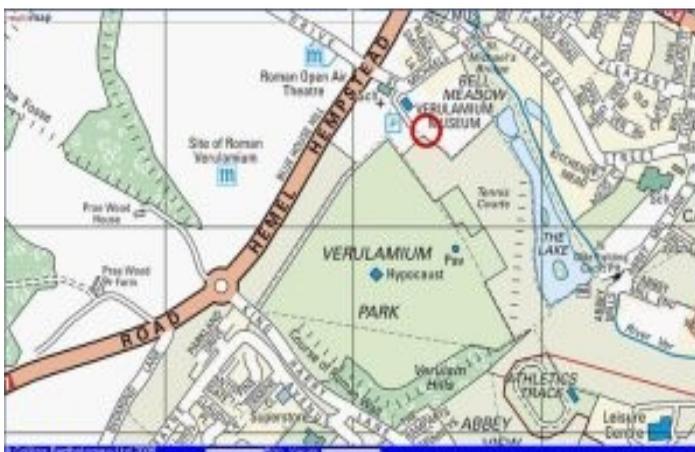
Hope to see you then.

Lesley Ralston

FUTURE EVENTS

Coffee morning for carers and past 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, £1.20.



Next date for carers meeting, at 11am.

Wednesday 20 November

We will be selling our Christmas cards and small gifts at the following locations this autumn.

Saturday 12 October, 10-1pm, Watersmeet Theatre, Rickmansworth

Saturday 26 October, all day, St Albans market

Friday 8 November, 10-3pm, Radlett Centre

Saturday 30 November 10-3pm Berkhamsted Courthouse

Wednesday 4 December 7pm Christmas Party

Come and join us again at The Noke, St Albans for some festive fun and mince pies. A chance also to get last minute Christmas cards.

Tuesday 28 January 2014, Abbey Theatre, St Albans

Once again we have been given a charity performance at the Abbey Theatre. This time the play will be *The Price*, written by Arthur Miller in 1968. Keep the date free, and watch out for more details in December.

Wednesday 2 April 2014, 7pm Branch AGM

This will take place at the Noke Hotel, St Albans, and after the AGM we will have a speaker.

DONATIONS

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

We recently received £65.59 from a collecting tin held in Rocha Dry Cleaners in Rickmansworth. Please let us know if there are any shops/pubs/restaurants in your area that would be willing to have a tin for us.

Thank you.

FUNDRAISING

Future collections

Welwyn Garden City, 23 November 2013

If you can help, for just 1 or 2 hours please contact Colin. We really need your help.

THE HUNT FOR 'HERO' GENES IS ON !

Today, a small number of people have a genetic advantage against MND. Tomorrow, with your help, that same advantage may be available to everyone.

Motor Neurone Disease is usually defined by rapid, relentless progression, but not in every case.

People often ask about Professor Steven Hawking – how come he has lived so long, despite having MND?

Treatments based on 'hero' gene variants could help the body push back against MND - If we can identify the genetic factors that enable some people to live for years after an MND diagnosis, then it may be possible to develop treatments that give that same benefit to everyone.

Identifying and understanding the 'hero' genes could turn MND into a disease people live with rather than die from.

This positive new research direction could provide a major turning point in the fight against MND, and it is essential that we fund as many research studies as possible.

To get more information from the MND Association, telephone them on 0845 751850 quoting 13SE, or go to the website at

www.mndassociation.org/get-involved/donations/September+Appeal

The MND Association is committed to supporting the widest possible range of pioneering research in order to develop treatments for MND. With your help, we can build a brighter future – perhaps even a future without MND.

The editor, Roland Lewis, has had Progressive Muscular Atrophy (a form of MND) for almost 14 years, so it looks like he has the hero gene.

CHRISTMAS CARD COMPETITION

Two years ago an artist donated a beautiful drawing to us - The South Herts Branch - which we had made into a Christmas card and sold together with the MNDA Christmas cards.

This year we decided to have a competition (in conjunction with The Herts Advertiser in St Albans, which is more or less in the centre of our patch) for a child to design a Christmas card, entry age up to 11 and 11-15. We thought it would be a really good profile raising exercise.

It's amazing how one thing leads to another! The editor of the newspaper turned out to be more than helpful (something I had never experienced from a newspaper before!) and now we have him as a contact. He knows the Mayor of St Albans, Cllr Annie Brewster and introduced me to her. They both helped us judge the competition, and we awarded 2 runners up prizes and one prize winner. See the winning design on the enclosed flier.

We had been one of the John Lewis, Watford, 3 charities in their in-store collection before Christmas last year.

We earmarked the £1000 we won for use on special occasions such as this. So we had prize money and were able to give the 2 runner's up £25 in gift vouchers and the winner £50 in gift vouchers. The Mayor presented the prizes for us in her chambers, and chatted to the children and their families for an hour and a half. See the photo on the front cover.

All this has meant I had to enter into correspondence and conversation with all three winners - Zoe who won and is 10 and Alexandra (15) and Jack (10). I also talked to their parents - who are thrilled that this has happened and to their schools in trying to sort out the date of the prize giving. I'm hoping that these new contacts will lead to other good things.

Already the Mayor of St Albans has agreed to come to a charity performance of the play *The Price* by Arthur Miller, which we are holding in January at The Abbey Theatre in St

Albans. She will conduct the raffle and make a short speech.

Zoe has turned out to be a rather lovely little girl, as she has donated half of her prize back to our branch. As I say on the back of the card, the words she has used in her design are the sentiments people feel, especially when they have loved ones who are ill, at Christmas.

The cards are 10 in a pack, for £2.50, with a loose sheet giving the information that is on the back of the card. Size 12.7cm x 12.7cm.

Please call me on [01923 778990](tel:01923778990) or email: leshenhouse@gmail.com if you would like to order some.

Lesley Ralston

INFLUENCING CHANGES TO STATUARY SERVICES

As you are aware, statutory services are being subjected to reforms and spending cuts. The MND Association is working to minimise the possible negative impact of these processes on people with MND.

As part of the NHS reforms in England, we are pushing to secure NHS funding for specialist MND services for the first time. We have already secured guidance which makes non-invasive ventilation (NIV) available on the NHS, and we are pushing for a guideline on MND as a whole, to make services more consistent. We expect this to be commissioned late this year and be completed in 2016. Social care is undergoing both cuts and reforms, which we are influencing through participation in the End the Care Crisis campaign, and the Care and Support Alliance.

Ultimately we want to ensure everyone with MND, and those who care for them, receive social care when they need it including free care at the end of their life.

St Albans 2013 Magna Carta Lecture by Professor Vernon Bogdanor in St Albans Cathedral

Thank you for inviting me to talk at this festival at St Albans, one of the five charter towns. The 800th anniversary of Magna Carta does not of course occur until 2015, but I believe that the discussions that led to it began at St Albans Abbey in August 2013. So this is a happy moment to lecture on that very significant document.



St Albans Cathedral

This summer, St Albans commemorates the 800th anniversary of its unique heritage as a Magna Carta Charter Town.

In 1213, churchmen and barons, led by Stephen Langton, the Archbishop of Canterbury, met at St Albans Cathedral to discuss their grievances against King John. This led ultimately to the sealing of the Magna Carta two years later.

The Magna Carta set out the basic rights and freedoms of common people, including the right to trial by jury. It also provided for regulation of the power of the monarchy.

Since the 13th Century, it has continued to underpin legal systems across the world and is still relevant today, forming the basis of the constitution of countries such as the United

States of America and Australia. We're celebrating our links with Magna Carta this summer with an exhibition at the Museum of St Albans until 15th September.

None of us should be in doubt that Magna Carta remains a living presence. Some years ago, in 2006, an opinion poll suggested that most people believe that Magna Carta day, 15th June, should be a national holiday. That was a timely rebuke to those of us who thought that Magna Carta had been largely forgotten; and that, if it was remembered at all, it was only through the immortal quip of the comedian, Tony Hancock, who asked, 'Magna Carta – did she die in vain?'

ST ALBANS GUIDES AT www.enjoystalbans.com

St Albans Tourist Centre produce an excellent annual printed Visitor Guide, which you can view on the above site or request a copy be sent to you. They also have a mini-guide, which is a condensed version of the brochure leaflet in English and other languages which describes all the places of interest to visit in the town.

If you would like a paper copy of any of these brochures, please contact St Albans Tourist and Information Centre on +44 (0)1727 864511 or by email to tic@stalbans.gov.uk



Mum, can you get me down now.

SIR DAVID FROST REMEMBERED

Tributes from around the world have been paid to Sir David Frost following his recent death. He was remembered for his legacy to ground breaking broadcasting but was also committed to supporting charities, including the MND Association.

He was Association patron and vice president for several years in the 1990s. Although critically acclaimed for The Frost Report and his interviews with the US President Richard Nixon, Sir David was probably more popular than ever during this decade thanks to his daytime show with Loyd Grossman, Through the Keyhole.



In 1993 he was knighted and also began presenting his long-running Sunday show, Breakfast with Frost.

Speaking in 1994 Sir David highlighted two people for drawing his attention to the 'great work of the MND Association.'

"Firstly there was the brave example of David Niven, valiant to the very end, and then there was the evangelism of HRH the Duchess of York. Either one was enough to persuade you about how deserving the MND Association is – together they made a case that was irresistible."

Sir David died aged 74 after a heart attack while on board the Queen Elizabeth where he was due to give a speech.

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

NEW FILM - HAWKING

On Thursday 19 September, in Cambridge, a gala première was held of the new film 'Hawking', about the life of MND Association patron Prof Stephen Hawking.

Following the première a live 'Question and Answer' session with Prof Hawking took place, which was transmitted by satellite to cinemas across the country.



The film is a story of Prof Hawking's life, told in his own words and those of his family, friends and fellow academics. It also includes contributions from Sir Richard Branson, Buzz Aldrin, Jim Carrey and Benedict Cumberbatch.

Reviews of the film, which was directed by Stephen Finnigan, include "Remarkably revealing and candid" (Sunday Times), "Brilliant" (The Sun) and "The Genesis of a Genius" (The Mail on Sunday). The film has also increased awareness of Motor Neurone Disease, with mentions on media ranging from BBC News, Daily Mirror and The Sunday Times to The Australian !

The gala première marked the start of this year's Cambridge Film Festival and also promoted the release of Prof Hawking's new book; 'Stephen Hawking: My Brief History – A Memoir', which is available to buy now.

Roland Lewis and his wife Jennifer attended one of the screenings in Watford. They both found the film informative, up lifting, and well worth seeing.

It will be on general release later in the year, and on Channel 4 after that.

BARBARA'S CLOSE ENCOUNTER OF THE THIRD KIND !

We went to a boot fair and as we were walking round, I engaged in one of my massive yawns (I can yawn for England, and believe it to be neurological and nothing to do with being tired). A lady with a stall on the market made a friendly comment. She asked me if I'd had a stroke, so I told her no, but that I had MND (I rather like it when people ask directly). Then she told me she was a healer, presented her cheek and said I should give her a kiss, which I did 'cos I'm very well behaved.

Then she smoothed out my hands and told me that every day I should scrunch up tight and then relax completely. She told me I should only wear cotton, no metal, visit the dentist regularly, keep smiling and be nice to everyone. So there you have it ! She was very sweet. It takes all sorts to make a world, and I have to say it was a very pleasant encounter. ☺

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.

JOKES FROM THE EDINBURGH FRINGE, 2013

Rob Auton - "I heard a rumour that Cadbury is bringing out an oriental chocolate bar. Could be a Chinese Wispa."

Alex Horne - "I used to work in a shoe-recycling shop. It was sole-destroying."

Tim Vine - "My friend told me he was going to a fancy dress party as an Italian island. I said to him 'Don't be Sicily'."

Gary Delaney - "I can give you the cause of anaphylactic shock in a nutshell."

**IF YOU WOULD LIKE TO DONATE TO
THE SOUTH HERTS BRANCH OF THE
MOTOR NEURONE DISEASE ASSOCIATION**

Do so in the following ways:

Send cheques to:

Mrs Alison Murdoch Treasurer South Herts Branch of the
Motor Neurone Disease Association, 41 Orpington Road,
Winchmore Hill, London N21 3PL

made payable to the MNDA South Herts Branch.

You can also donate online at [Localgiving.com](https://www.localgiving.com).

Please follow these steps:

Go to [localgiving.com](https://www.localgiving.com)

Type mnda in the box at the top right of the page called
SEARCH

Make your payment to the South Herts Branch of the MND
Association

PLEASE NOTE: If you are a taxpayer, please consider
ticking the gift aid box. We will then receive an extra 20% on
top of your donation – so if you donate £10, we will receive an
extra £2.50.

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.

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

