

South Herts Branch APRIL 2013 NEWSLETTER



See inside for more information

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

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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 APRIL 2013

Thank goodness we have had a glimmer of sunshine in the last few days – an incentive to grit our teeth and wait for Spring to finally arrive. I've got a few miniature daffodils coming out in my garden, which are another sign that Spring is on the way, and as I sit here typing I am looking at them.

It's the AGM on Wednesday 3rd April at 7pm at The Noke Hotel, Watford Road, St Albans AL2 3DS. I think this will be a fun evening as we have the lovely Liz Garrod coming to talk to us and she is a jolly lady ! As you probably all know by now, Liz is the Coordinator and Project Lead for Rare and Rapidly Progressive Neurological Conditions for Hertfordshire, and the continuation of her post is now looking more optimistic. Please do come, the business will not take long and there will be light refreshments and a chance to catch up and meet new friends afterwards.

We will have a raffle and we have some really good prizes.

Also greeting cards and other things for sale, to raise money for South Herts Branch – but please don't feel obligated !

John Lewis in Watford will be coming to the AGM to present us with a cheque for the charity collection, which took place in the last quarter of 2012. We were one of 3 charities and John Lewis are giving us a cheque for £990. Last year we were also in Waitrose as one of their charities, twice!

Many of the supermarkets now have instore collections for charities, one way or another. So far we haven't been successful in any other one. Please look in whichever supermarket you shop in, and see how their scheme works – you may need to fill a form out and if you need any help please give me a ring.

We also have a Quiz Evening arranged for Friday 3rd May at 7.30, in St Stephen's Church Hall, St Albans. This is at the top of Holywell Hill/St Stephen's Hill but the entrance is actually in Watling Street. It is a lovely venue and promises to be a good

evening. There will be fish & chips at half time and I have it on good authority that the fish and chips are delicious.

Please bring your own drinks/nibbles and a glass as well.

Don't worry if you forget the glass, we will have a small supply of disposable cups just in case. There is a flyer enclosed with all the information. Why not make up a table – of up to 8 people. Places are limited, so book quickly.

We're also planning a Barn Dance to take place in October – more information in the next newsletter when arrangements have been finalized.

We are presently looking at possible venues to hold some drop in/get togethers for people living with MND, their carers, friends and families. We are thinking about a nice pub, perhaps with a garden – if you know of a possible venue, please let me know. It would have to be wheelchair accessible and have plenty of parking space. We would buy the first drink and provide sandwiches.

I really look forward to meeting you this year – all our (for want of a better word) meetings are very friendly and casual. We all have something in common and can help each other by meeting up.

Lesley

FRONT COVER

We recently attended a social function held by the branch we used to belong to, Reading and West Berkshire. We met Sally Light, the new Chief Executive of the Association, who was very friendly and said that she was enjoying her new role tremendously. I also caught up with my neurologist, Martin Turner, Consultant Neurologist and Oxford MND Care Centre Co-Director. I have helped him with several research projects over the past 10 years, so he is always pleased to see me !
Photo from L to R - Martin, me, Sally, Daphne from the Reading branch and my wife Jennifer.

Roland Lewis

FUTURE EVENTS

NOTE*AGM***NOTE***AGM***NOTE***AGM***NOTE**

Wednesday 3rd April at 7.00pm Branch AGM

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

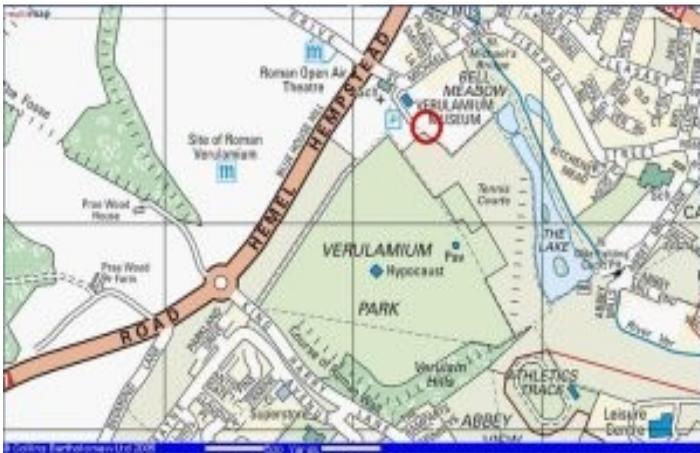
After the short business of the meeting, there will be a talk by Liz Garrod who is the Coordinator and Project Lead for Rare and Rapidly Progressive Neurological Conditions for Hertfordshire. If you are living with MND and would like help with transport to the meeting, please get in touch.

Friday 3rd May at 7.30pm Quiz Evening

This will take place in St Stephen's Church Hall St Albans. See the enclosed flyer for more details.

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 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 have been sent out with the winter Thumb Print, or go to

www.mndassociation.org/news-and-events/events/conferences/spring-conferences

NAIDEX NEC BIRMINGHAM

30th April to 2nd May Free Registration

Naidex is the UK's largest disability, rehabilitation and homecare event with over 300 exhibitors featuring the latest products and services to aid independent living.

www.naidex.co.uk

DONATIONS

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

One of the donations we have recently received is, Waitrose, Rickmansworth £817

FUNDRAISING

Street collection dates for this year.

Berkhamsted	11 May 2013
St Albans,	18 May 2013
Rickmansworth M&S	15 June 2013
Harpenden,	20 July 2013
Welwyn Garden City,	23 November 2013

20th ANNIVERSARY OF THE SOUTH HERTS BRANCH

The South Herts Branch of the MND Association celebrates its 20th anniversary this year!

Here is a brief history as to how it all began.

Harry Riddle, the first Chairman of the Branch then yet to be formed, he having been diagnosed with MND in July 1992, organised a meeting at St Albans City Hospital inviting local support groups, social services, representatives from National Office, etc. Forty three people attended that initial discussion group.

The object of the meeting was to establish whether there would be enough volunteers to form a group Committee, there were – the only time this had happened nationally at an initial meeting. The newly formed Committee met for the first time at the City Hospital on 17th February 1993, the first open general meeting was on 3rd March.

It usually takes a full twelve months for a group to be granted full Branch status by National Office but South Herts was accorded such at its first Christmas party on 1st December 1993, when representatives from National Office attended. That meeting was held at the Jubilee Centre, St Albans, which was to remain our meeting place for many years. After Harry Riddle died in April 1994 his daughter Margo succeeded him as Chairman.

Today in 2013, twenty years later, the South Herts Branch, under the present Chairmanship of Lesley Ralston, continues to offer support those with MND and their carers throughout South Hertfordshire.

Mark Macan-Lind

OUR ROYAL PATRON SHOWS HER SUPPORT



We recently welcomed 70 guests to a reception in support of funding for our Oxford Centre for MND Research and Care. Held at The Royal Society in London on 29 January, the reception was attended by our Royal Patron, HRH The Princess Royal. She spoke of her own personal connection to MND through a friend who is living with the disease. She also stressed the vital role of research and the progress being made.

Kevin Talbot, Co-Director of the Oxford Centre and Professor of Motor Neuron Biology at the University of Oxford explained to guests the work of the Centre and the importance of research and care working hand in hand.

Sally Light, our Chief Executive said: "It was a fantastic evening and we were delighted to welcome our Royal Patron, HRH The Princess Royal. One of the highlights of the evening was the inspirational message from Ashley Morgan who spoke powerfully about living with MND and underlined the value of our continued efforts in both research and care."

MND Association

STEPHEN HAWKING on DESERT ISLAND DISCS

Cut off from normal physical life and deprived of natural means of communication, was Professor Hawking, asked Sue Lawley, already familiar with isolation ?

“I don't feel a disabled person,” he told her, when he appeared on the programme. “Just someone with certain malfunctions of my Motor Neurones. I suppose my life can hardly be described as normal, but I feel it is normal in spirit”.

Lawley suggested that, unlike most castaways, he was already mentally and intellectually self-sufficient. The she asked, “but what about emotional fulfilment, Stephen ? Even a brilliant physicist must need other people to find that ?”

He replied, “I couldn't carry on my life if I only had Physics. Like everyone else, I need warmth, love and affection.”

Hawking claimed to have worked for just one hour a day whilst studying for his first degree at Oxford - “the Physics course at the time was ridiculously easy” - and filled the rest of his time with traditional student activities like rowing and drinking beer.

Lawley asked him about a comment he had made in the past that he was happier since falling ill.

“I certainly am happier now,” he confirmed. “Before I got Motor Neurone Disease I was bored with life – but the prospect of an early death made me realise that life was really worth living.

“I don't think Motor Neurone Disease can be an advantage to anyone but it was less of a disadvantage to me than to other people because it didn't stop me doing what I wanted which was to try and understand how the universe operates”.

Stephen's book was George Eliot's *Middlemarch*, and he also planned to take a large supply of crême brulee. “For me, that is the epitome of luxury “ he said.

Campers: Nature's way of feeding mosquitoes.



The fact that you are reading this means that you have a link of some sort to the MND Association and an interest in its progress and success in supporting and campaigning for those living with the disease. Because of this, you may be able to help in recruiting people into a new category of membership – ‘Friends’ of the Association.

As you know, the Association is a membership organisation but you may not realise that we have almost 8,000 members across different membership types.

Our personal members include people with and affected by MND, supporters and volunteers, and that gives them specific rights, including the ability to elect Trustees and to take part in governance activities such as attending our AGM. Personal members also receive benefits including receiving a printed copy of our exclusive members' magazine, Thumb Print.

We also have professional members, the majority of whom are health and social care professionals.

Members are important to us because not only do they provide vital support for the ongoing work of the Association, but just as importantly, they help strengthen our voice and increase our influence on central Government and local authorities.

Becoming a member is a strong statement of support for all people with MND, their carers and families. Each and every member adds to our collective voice.

The Association has reviewed and revised its membership strategy, and the most significant change is the introduction of a new, online initiative called ‘Friends of the Association.’

The purpose of Friends is to recruit a new type of supporter who wants to engage with us online and prefers to belong to a 'virtual' community. Being a Friend provides a way for individuals to show their support but without the full membership package which may be less relevant and appealing to them.

MND Association

STREETLIFE

Sign-up to www.streetlife.com to spread the word about how you make a difference to the life of people with MND in your local area. All you need to do is type up your postcode, create your profile and give your branch or group's details.

The News

Change is inevitable, except from a vending machine.

bake it!
and help make MND history

After the great success of last year's fundraising campaign during awareness month, 2013 will see us encourage supporters to 'bake it !'

If you love to bake why not use your talents to raise funds for your branch or group? Holding a cake stall, bring and buy, coffee morning, friends' lunch, afternoon tea or a 'Come Dine With Me' party are great ways of raising awareness and funds. Up for some great fun and food? See MND website for details www.mndassociation.org

MND Association

INCURABLE OPTIMIST HONOURED WITH A BEM



Patrick Joyce, who fronted the MND Association's 2010 Incurable Optimism campaign, was honoured with a British Empire Medal (BEM) in the 2013 New Year Honours List.

Patrick, along with Rosemary Pack from Essex, are both living with Motor Neurone Disease (MND) and they together with Lino Pires, a local businessman have been recognised with the BEM. The newly-reinstated British Empire Medal for Services to the Community have been presented to extraordinary people like Patrick right across the United Kingdom in recognition of their achievements in charitable or voluntary work.

Patrick, who lives in Wells, Somerset, with his wife Kathy and their three children Reuben, Elliot, Nancy, was diagnosed with Motor Neurone Disease (MND) in 2008.

When he received his diagnosis he gave up painting but took it up again to front the Association's 2010 Incurable Optimism awareness campaign under the name [Patrick the Optimist](#).

As a way of demonstrating his own optimism, and to inspire others to raise funds and awareness of MND, Patrick set himself the challenge of painting 100 portraits depicting incurable optimists from the MND community. Patrick's efforts were promoted on the London Underground and portraits themselves exhibited at the Houses of Parliament.

Speaking at the time about the campaign, Patrick said: *"I have found out first hand what MND does to individuals and their families. I want to get better care for me and my fellow sufferers and I want a cure.*

"To do this we need to raise awareness and get more money for research. I will not get to see my daughter go to school and want to do anything I can to stop that happening to others."

101 – POLICE NON-EMERGENCY NUMBER

101 is the number to call when you want to contact your local police – when it's less urgent than 999.

101 is available 24 hours a day, 7 days a week.

For example, call 101 if your car has been stolen, your property has been damaged, to report a minor traffic accident etc.

Calls to 101 (from both landlines and mobiles) cost 15 pence per call no matter what time of day you call, or how long you are on the phone.

More information on the 101 number and how it works can be found at www.police.uk/101

'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

EDITOR'S NOTE

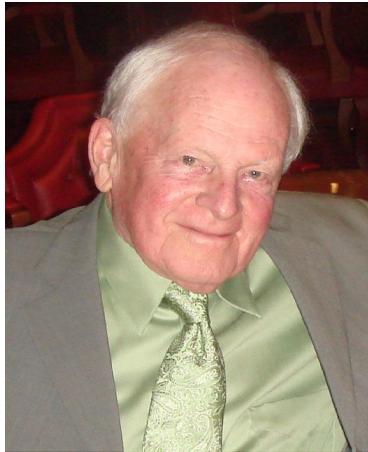
If you would like to receive the newsletter by email, to help cut our costs, then please let Jennifer Hay know at rollewisjenhay@gmail.com

STREET COLLECTIONS

If you can help, for just 1 or 2 hours, please contact Colin.

***** We really need your help*****

REMINISCENCES PAST AND RECENT



I first became aware of the South Herts Branch of the MND Association on the actual day that my late wife, Dorothy, died from the disease in 1995. The post that morning included a letter, addressed to her, from Eunice Riddle - then the Branch contact - explaining that one of the aims of the Association is to offer help and support to those with the disease, and to those affected by it. Eunice's deceased husband, Harry, had been the founder of the South Herts Branch.

I started to attend Branch meetings to find out more about the Association, wondering if I could help in any way, but my attendances ceased for some months after I fell and broke my left leg in two places. When mobile again I resumed attending the Branch meetings and was later elected to serve on the Committee, eventually to become Vice Chairman and Secretary, working closely with the then Chairman, John Barton. I remained Vice Chairman and Secretary of the Branch for many years, also editing the Newsletter at that time.

My apologies to some of the older members of the Branch who may be thinking: "Why is he telling us all this, we know the history!" But it may be of some interest to those members who have joined the Branch more recently.

Early in March I returned from vacation in Florida, having escaped our UK winter for three months. I have been fortunate in being able to do this for the past four years, staying with the widow of an old friend, in Kissimmee, near Orlando. Let me explain, I must go back many years!

In 1961 Dorothy and I lived in north London. We became good friends with a couple living next door, Michael and Kathleen. We always remained in touch, long after we had each moved our separate ways. In 1977 Michael's work took him to Florida, where he remained until his death in 2002.

In 1987 Dorothy and I had gone on holiday to Florida, staying with Michael and Kathleen. Whilst there I hired a car and drove to the Gulf of Mexico coast, then south to the town of Naples, east through the Everglades to Miami and then north along the Atlantic coast, returning to Cocoa Beach, where Michael and Kathleen lived at that time.

On my recent visit to Florida, together with Kathleen, I retraced my 1987 journey that I had made with my wife Dorothy, hoping to bring back memories of that earlier tour, but the memories were few. So many changes have taken place during the intervening twenty six years!

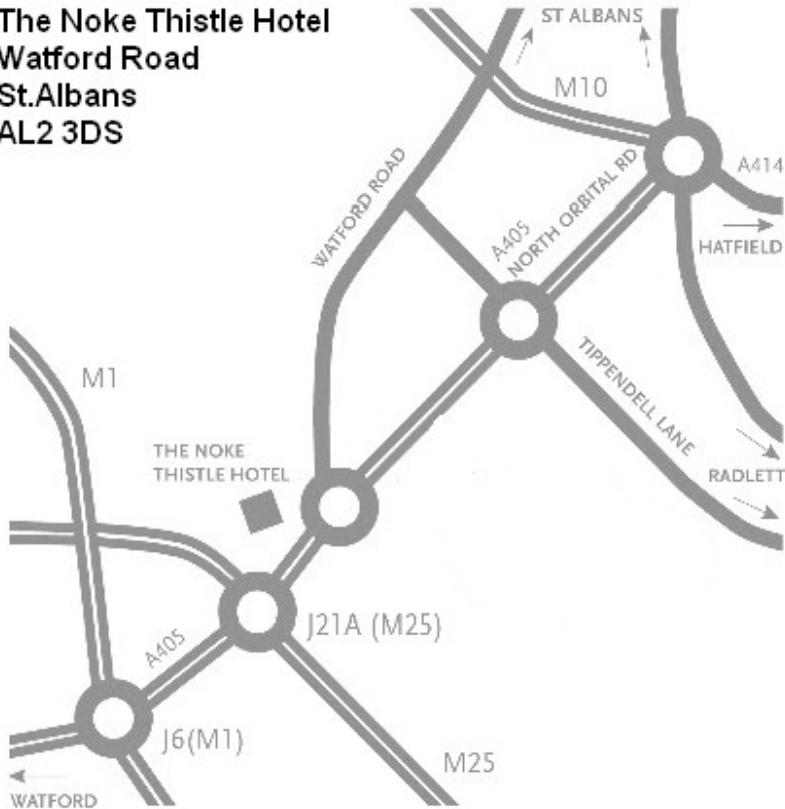
But the recent drive was very enjoyable, with highlights I shall long remember, an airboat ride through the Everglade swamps and getting out of the car, maybe unwisely, to photograph a large alligator by the roadside. A visit to a native Indian settlement was very interesting. There was the inevitable tourist gift shop, but filled with beautifully crafted jewellery and clothing, not the usual trash that many tourist places so often offer. Also there is a museum devoted to American Indian culture and history. A must for any visitor!

Mark Macan-Lind

You can't have everything; where would you put it ?

I took an IQ test and the results were negative.

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.