



South Herts
Spring 2015
Newsletter
Our Branch Website
www.mndsoutherts.org
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www.facebook.com/mndasoutherts

Eddie Redmayne wins Oscar for The Theory of Everything

In this issue



MND Connect is the National Office Helpline
mndconnect@mndassociation.org
www.mndassociation.org

Motor Neurone Disease Association – Registered Charity No. 294354

**Patron – Dr Carol Scholes
Macmillan Consultant in Palliative Medicine**

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Jennifer Hay	Vice Chair	01923 720 198
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Rosemary Lingwood	Collection Organiser	01525 377 450
Liz Pybus	Regional Care Development Advisor	08453 751 840
Maggie Coles	Secretary	01727 854 583
John Whale	Committee Member	01727 761 611



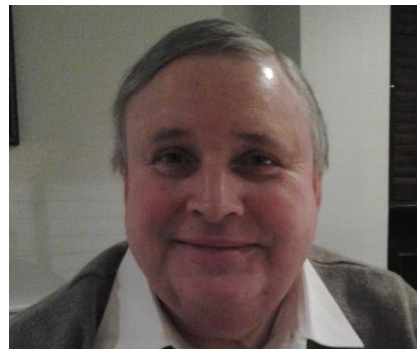
Chair's Report
Our Chair's round up of the summer and our past events.

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 (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.

'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



New Committee Member

Donating

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

Cheques should be made payable to the MNDA South Herts Branch.

You can also donate online at www.Localgiving.com

Please follow these steps:

Go to 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.

Chair's Report

CHAIR'S REPORT SPRING 2015

I'm sure you haven't missed the fact that this newsletter is totally different to previous ones. Circumstances have changed and the newsletter will be in this format in the foreseeable future. All the information included will be exactly the same as before, plus there may be information from the MNDA as well.

I'd like to start by saying what wonderful year we had in 2014. The best part was the cementing of our get together's for people with MND, their carers and families. They have been phenomenally successful and Jenny Fellas Elinor Mumford and I feel so proud and touched by the lovely people who come. They have all got to know one another and bonded, becoming friends and keeping in touch with one another, sharing information.

2014 was also a wonderful year for fundraising. We were able to help so many people. So many people chose South Herts Branch to donate to.

Events

BRANCH AGM

Wednesday 1 April at 7.30pm
The Noke Hotel, Watford Road, St Albans AL2 3DS.

GET TOGETHERS FOR PEOPLE LIVING WITH MND

April 8, May 6, June 3, July 1, August 5, September 2, October 7, November 4, December 9. 2pm.
Box Moor Trust centre, London Road, Hemel Hempstead, HP1 2RE

QUIZ EVENING, FRIDAY 1 MAY, 7.15 FOR 7.45

St Stephen's Church Hall St Albans

STREET COLLECTIONS

St Albans 18 April
Berkhamsted 2 May
Harpenden 25 July

FOR SALE

DISABLED ADAPTED VEHICLE. FULL HISTORY FROM NEW. 2 OWNERS RENAULT TRAFIC T1100 1997

Full year MOT. 20,000 miles. Petrol. Blue. Power Steering Seats 5 and space for 2 wheelchairs.

Folding ramp at rear and hydraulic winch.

£16,000.

Phone: Sheila Gee 0208 866 8923 jands.gee@talktalk.net

Thank you all those people who helped and supported us.

The icing on the cake was The Ice Bucket Challenge which not only created so much revenue for MNDA (much of which will be used for scientific research) but also for our branch. But importantly raised the profile of Motor Neurone Disease and that has in turn created lots of opportunities and possibilities.

Jen (my deputy chair) and I went to the premiere of the film The Theory of Everything. It was so exciting. We stood by the 'red carpet' and saw all the stars – Prof Hawking, his first wife Jane (who gave me her autograph which I intend to raffle if I manage to get Eddie Redmayne's !) Eddie Redmayne and Felicity Jones, who played Jane. The film is amazing and Eddie Redmayne has received all the awards, culminating in the Oscar as best actor, for his incredible portrayal of Prof. Hawking.

The film is now showing locally, and luckily for us, the Rex cinema in Berkhamsted and the Odyssey cinema in St Albans (both in our area) are having lots of performances. We have been having bucket collections at those two cinemas. People have been generously donating a lot of money for our branch.

In January The Abbey Theatre in St Albans donated another charity performance to our branch for which we are very grateful. It was Therese Raquin by Emile Zola and I thoroughly enjoyed the play.

In February I went to St Clement Danes School in Chorleywood to collect a cheque. The school chose us as one of 4 charities to collect for at their charity event in December. I have to say that the three other charities were really laudible ones such as children who are captured for slavery, and children and teenagers who have eating disorders. They raised an incredible amount of money and we received £2500 as our share. A wonderful start to the year.

Our next function is our AGM on Wednesday 1st April at The Noke Hotel, 7.30pm as usual. We are lucky enough to have our wonderful patron, Dr Carol Scholes talking about local developments in palliative care.

We have our annual Quiz Night coming up on 1st May. Do please come and support us. Further information in the newsletter.

Lesley Ralston

Future Events

BRANCH AGM

Wednesday 1 April at 7.30pm

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

Please join us for our AGM.

After the short business of the meeting, there will be a talk by our Patron Dr Carol Scholes. The subject of her speech will be 'Local Developments in Palliative Care'.

If you are living with MND and would like help with transport to the meeting, please get in touch.

GET TOGETHERS FOR PEOPLE LIVING WITH MND

These are informal gatherings in a place where people living with MND and their carers and families can meet in privacy, and chat together informally in a calm and safe setting.

The venue is the Box Moor Trust centre, London Road, Hemel Hempstead, HP1 2RE.

If you need transport or any more information, please contact Jenny Fellas on 01582 621387 or chris_jennyfellas@hotmail.com

The meetings start at 2pm, and will be held on Wednesdays.

Dates for 2015 are April 8, May 6, June 3, July 1, August 5, September 2, October 7, November 4, December 9.

QUIZ EVENING, FRIDAY 1 MAY, 7.15 FOR 7.45

Please join us for our popular quiz evening at St Stephen's Church Hall St Albans.

Tickets at £15 include a fish and chip supper.

See the enclosed flyer for more details.

STREET COLLECTIONS

We are holding the following street collections and would be very grateful if you could spare an hour or two to help.

Please contact Rosemary Lingwood if you can help.

St Albans 18 April

Berkhamsted 2 May

Harpenden 25 July

OBITUARIES

WE WILL REMEMBER THEM

These two special people died recently. These are my memories and some information about them.

COLIN GULLIVER was already on the South Herts Branch committee when I became chair in 2009. Colin's mother had MND and he attended meetings with his father for many years, joining the committee in April 2006. He has been a stoic, dependable and loyal friend to all of us on the committee. He stored boxes and boxes of our things in his loft, and would bring them to meetings, never allowing us ladies to do anything. Colin applied for permits from the councils for street collections in his area of Herts, arranged the collectors, banked the money and did it all over again the following year without fail. I often used to say – at our AGM ! – Colin was the one of the people I most valued on the committee.

Colin was a modest quiet man. He had Crohns Disease for some time and latterly, cancer. He had no family, but our thoughts are with his friend Wendy who was his companion for the past few years, and we got to know her she accompanied Colin to all our events.

We have a deep affection for this sweet, gentle and generous man and will miss him.

ROLAND LEWIS (husband of my deputy chair, Jennifer Hay) was one of those members of an exclusive band of brothers/sisters with MND, who managed to beat the disease for more than 15 years. I'm not surprised (although I am not saying he did it by anything more than luck of the draw) – he was a strong, determined and self controlled man, who never (outwardly) let the disease get him down. That allowed him and Jen to have time to come to terms with a disease which, although seemed to be never ending, was inevitably terminal. Although maybe that made it harder.



Colin Gulliver



Jen & Roland Lewis

WHEELCHAIR ACCESSIBLE CAR FOR SALE

Mercedes Vaneo, 1.6
Ambiente Manual Petrol,
2007, Silver.

4 Seats plus room for
wheelchair.

Inside height of 61 inches
makes it very suitable for taller
people.

Full service history. Mileage
47,500.

Price £10,995

Contact Jennifer Hay 01923
720198 or

rollewisjenhay@gmail.com

When I joined the committee in 2009 Ro was still walking, albeit with difficulty. As happens with MND things started to deteriorate fast, and soon he was unable to walk. He tried to attend committee meetings with Jen and usually did, but he was always worried about her and the possibility that she might have to deal with an emergency situation. He knew how hard it is to look after a person with MND, regardless of their symptoms and he always made sure that things were OK for Jen. Roland became totally paralysed. He could however, eat and speak. He had a dry sense of humour and a quiet wit. Took me a long time to work him out! I hope he thought of me as a friend. I will try to look after Jen.

I am so glad that, although hard for Ro's last year, he had those years of slow progression of the MND, when he and Jen managed to travel (lots!) and enjoy life in their happy marriage and the memories which I know Jen treasures.

Lesley Ralston



THE NEWEST MEMBER OF OUR COMMITTEE IS JOHN WHALE. HERE HE TALKS ABOUT HIMSELF AND THE REASONS THAT HE JOINED THE MND ASSOCIATION.

When I took early retirement in 2010 I knew that I wanted to do some voluntary work, but I never dreamed that part of it would be serving on the committee of the South Herts branch of the MND Association. Back then I had hardly heard of MND and the terrible effect of the disease.

Two years later I noticed that my friend Charlie's speech was slurred. As we were at a beer festival I didn't think a lot of it, but sadly it wasn't the beer, it was the start of MND. A few months later the disease was diagnosed. At least it's not cancer I thought. Nothing could be worse than that. Until I googled MND and to my horror found out that it is worse than cancer. At first Charlie was still full of life, but as she was a nurse she knew what was coming. I saw the gradual deterioration of my friend, who sadly died last November. I was only happy, back when she was first diagnosed, that I was able to help her put her various pensions and financial

affairs in order, and negotiate an immediate full payment of her occupational Pension. I joked that if she survived MND she could blame me for being poor. Sadly, of course, she didn't. It was also me who first found the MNDA website, and put her in touch With her local branch in Canterbury. Since then she has campaigned long and hard for them, even having an article about her in the local paper. It is she who inspired me to become involved. She inspires me still. I was born and raised in Hendon, and it was when working as a Civil Servant after I left school that I became interested in unions. The first in a series of happy accidents in my life. After serving for 3 years as a full time representative I couldn't stand the tedium of pushing a pen in an office, and was fortunate that a friend saw an advert for a job with Usdaw (another happy accident). I applied for it, got it and so started 31 years in a job that I loved, supporting shop workers, negotiating, training reps. and building the union. I eventually retired at 56. I loved work...but I love retirement more! As I have said I decided to do voluntary work, but what? Initially I did some work with Mind, and still do help out very occasionally if people need work related advice or advocacy. I then joined Victim Support as a Community Volunteer. That involves helping and supporting victims of crime, offering emotional and practical support. And guess what? I also ended up as the Divisional Advocate (or union rep) for the volunteers in Essex and Herts. Is there no escape from my former life? Every Tuesday I work at the CAB as an adviser. It is very

rewarding work, and has taught me a lot about areas of law, and people's rights and responsibilities. It enabled me to help Charlie, and I hope that I can use those skills in the MNDA. I also enjoy a lot of hobbies, one of the main ones being the hospital radio show I present at Barnet hospital every Thursday. I have been working in hospital radio on and off for over 34 years. One day I will learn how to do it! I spend a couple of months a year in Bulgaria, Nessebar to be precise, enjoying the beautiful Black Sea. I also spend many long weekends at my caravan in Kent. In the summer I can often be found in Canterbury watching Kent play cricket. A mixed experience! My first 3 months in the MNDA have been quite hectic. Selling Christmas cards in Berkhamstead, holding a collection box (unfortunately my hand has an uncontrollable nervous rattle when it is holding one of those) in WGC, appearing on Radio Verulam to talk about our work, wearing a daft Jester's hat at the Christmas party and attending our charity play, Therese Raquin. Phew!!! I am looking forward to continuing working with you and everyone involved in the MNDA South Herts branch to support those suffering from MND, and to help to find a cure for this terrible disease. Charlie, look what you have started...

THANKS TO THE NOKE THISTLE HOTEL

We are extremely grateful to Bob Dowry, 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.Aibans
AL23DS**

