

## Rotary Donation



Pictured, from left to right, are, Rosemary, Jenny, Alan, Lesley, Jennifer, Sian and Alison

Mr Alan Rice-Smith, from the Brookmans Park Rotary Club, came to one of our committee meetings, to tell us about the work of Rotary and to present us with a

cheque for £1,000. We are extremely grateful for this generous gift.

**mndconnect**  
0808 802 6262  
mndconnect@mndassociation.org

MND Connect is the National Office Helpline. Please get in touch if you need any assistance or have any questions.

## Post or email?

Are you receiving this newsletter through the post? If so, would you like to get it via email? Each copy we print and post costs the branch about £1.

If you wish to continue to get the paper version, or don't have access to a computer, that is perfectly fine.

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[info@mndasouthherts.org](mailto:info@mndasouthherts.org)

or telephone:

01923 720198

# Chair's Report

Well, we're probably all saying it – but I don't know where 2017 disappeared to!

I hope you all had a good and uneventful Christmas – I had a few mishaps such as the kitchen sink blocking up on Christmas Eve! All of us at the South Herts Branch wish everyone a good 2018.

On the subject of Christmas, I hope the small band of stalwart supporters who used to come to the Christmas party were not too disappointed that we didn't hold one this year. We've decided to try something else instead.

We are holding a new event in 2018 (an alternative to a Christmas party). This will be held on Saturday March 10th and I hope you will all drop in and have some lovely homemade cake. See more information in this newsletter.

We had our annual Ladies Lunch at Chenies Manor again in September, when we raised £1,231. The venue really makes the event and I can't imagine holding it anywhere else. Mrs Macleod Matthews has agreed that we can hold it there again in 2018 and I am very grateful for that. We will let you know the date soon and I hope you can all come. Please note, book early!! It has got to the point that the same people come every year and as the venue space is limited we often have to turn people away.

We also still use the same wonderful caterer, Amanda Clements. The food is delicious and is of a very high standard - lots of praise.

Due to unforeseen circumstances we had to cancel our annual quiz night last year. I hope you were not too disappointed and you will come to this year's – date to be announced. The quiz master, Mike Fisher, has agreed to come and conduct proceedings again.

Get togethers for people with MND, their carers and families continue to be very well attended and a great success. Neil Penson from National Office came to the last one and previously we had Katie Sidell,

a neurologist from The National Neurological Hospital in Queen's Square, London. We also had a trainee speech and language therapist, Ellie Matthews, come to the one in December.

A small band of people are starting to come to the new ex carers get togethers we hold at The Three Hammers pub in St Albans. They are very informal and the next one will be held on Thursday 1st February at 12 o'clock. We usually treat ourselves to sandwiches and baked potatoes and have a good natter. Most people have met previously at the get togethers for people with MND, but if you would like to come and you haven't been recently, you would be more than welcome. It is very friendly and informal. Give me a call for a chat – 01923 778990. We don't hold these on a regular date so check with me to find out the date if you are thinking of coming.

The AGM will be held on Wednesday 4th April at 7.30 and will be held at The Noke Hotel, as usual. Laura Wrangles will be our speaker this year. Laura has been the Navigator of Care for people with Rare Neurological Diseases in Hertfordshire, for a year now.

Finally, it sounds as if the recent Parliamentary Reception on 17th October 2017 was very successful. I was unable to attend but we have an excellent report by Helen who is a regular contributor to this newsletter.

**Lesley Ralston, Chair**

## If you would like to donate to the branch:

Send cheques payable to the MND South Herts Branch to:

**Mrs Alison Murdoch, 41 Orpington Road, Winchmore Hill, London N21 3PL**

Or donate online at [Localgiving.com](http://Localgiving.com) by entering mnda in the search box.

PLEASE NOTE: If you are a taxpayer, tick the gift aid box. We receive an extra 25% on top of your donation, at no cost to you.

## Thank you very much.

# To all our friends and supporters Please drop in to...

St Stephens Church Hall,  
14 Watling Street, St Albans, AL1 2PX  
On **Saturday 10th March 2-4pm**

Over the years we've had so many supporters and contributors who have raised and donated money to us.

We would like to thank those people and all the other people - health care, social care and other professionals. We'd like to be able to meet those people we have supported and who have supported us over the years.

Instead of meeting up for Christmas on a cold, dark evening in December, we have decided to invite you all to a drop in on a Saturday afternoon in March. We have made so many friends over these last 10 years since I became Chair and we were able to set up our committee in its present form.

It would be lovely to meet you all again, to thank you and become reacquainted. We will be having refreshments (home made cakes !)  
All will be welcome – bring all your family and friends.

We are thrilled to have The Rickmansworth Players coming to sing us songs from the musicals as an added treat.

St Stephens Church is opposite the King Harry Pub at the top of Holywell Hill leading down into St Albans. You need to turn into Watling Street at the roundabout, and the turning to the church car park is the first on the left.

Lesley Ralston



# MNDA Parliamentary Reception

This event, held on 17th October 2017, was jointly hosted by the MND Association and the All-Party Parliamentary Group (APPG) on MND, who launched their report on access to Personal Independence Payment (PIP) for people with MND. PIP is a benefit for people aged under 65 to help pay for the extra costs of living with a disability or health condition. Following an investigation, the APPG found that people with MND are experiencing problems throughout the PIP process – from finding out about the benefit in the first place, to gathering medical evidence to support their claim, being called for a face-to-face assessment and then being reassessed unnecessarily.

Charlotte Hawkins, Good Morning Britain presenter and Strictly Come Dancing star, whose father died of MND in 2015, was one of the speakers at the event. She opened up about how MND affected her family, and urged MPs to help people with MND to get the financial support and benefits they are entitled to, at the right time.



Helen with Alberto Costa MP for South Leicestershire, on the right.

Helen, a member of our branch, who is living with MND, attended the day and wrote about her experience,

“I attended this Reception as a South Herts Branch patient. It was held in the Queen Elizabeth 11 Centre opposite Parliament. The event was co-hosted by the All-Party Parliamentary Group of MPs. The Group had been looking into MND patients’ experiences of applying for Continuing Healthcare Payments and Personal Independence Payments (PIP). It was well-attended with a good buzz of conversation in the room - a better location than Church House in previous years.

Richard Harrington, MP (Watford) had said he would attend the Reception. Oliver Dowden MP (Hertsmere) had commitments at that time but said he would attend if these permitted. David Gauke MP (South West Hertfordshire) had declined.

No local MPs turned up but I did speak with Alberto Costa, Conservative MP for South Leicestershire. He was very keen to hear patients’ experiences about the cost of living with MND and asked his researcher to exchange emails.

Chris Evans MP made a passionate plea to MPs in the room. He asked MPs to support MND patients getting Disability Living Allowance to transfer to Personal Independence Payments (PIP) on the same level of money, without going through reassessment. He asked for changes in how MND patients are assessed for PIP because of problems found - interviewers and those deciding applications lacked knowledge of MND, some questions were too crude to properly take on board what patients can and can’t manage, assessments are out-of-date sometimes as the disease has got worse while awaiting a decision.

An MND patient with three young children spoke about taking the Department of Work and Pensions to

Court and won his case. He had been getting PIP. This was cut when he was reassessed, despite having got worse during this time.

Charlotte Hawkins, TV presenter, recalled with grief, watching her father deteriorate and pass away with MND and her commitment to supporting the Association and patients.

Penny Mordaunt MP, Minister of State for Disabled People, Work and Health said that reassessments for MND patients getting Employment and Support Allowance had been scrapped. She spoke about linking health and social records for new claimants for Employment and Support Allowance Work Support Group. These are unemployed people under 66 years who are considered able to return to work with support, or who cannot work at all. The plan was to reduce bureaucracy and make things better for claimants. Claimants' social records would provide information towards their Benefit claim. The Minister did not say what someone's 'social' records actually were. I found it very confusing.

It was worthwhile going to the Reception. The financial cost of living with a disease that will only get worse, without any idea of costs to be faced, is important to everyone. I got chatting to other patients. I was impressed with the work of the MPs in the Parliamentary Group. They knew about Benefits' rules. They understood how the rules can work against you when you're not well in the first place. They understood how paperwork, attending assessments and delays create more stress and anxiety. And can never capture what MND has done to your life and your family.

Marta (former carer of Glenn Phillips) came along with me. Marta did the driving, helped me around and kept me topped-up with coffee - and took photos. Thank you Marta."

Helen

## Ladies Lunch

Once again our ladies enjoyed the venue at Chenies Manor, the wonderful food and all the chatter ! Our thanks go to Mr and Mrs Macleod Matthews for letting us hold the lunch at the Manor, once again.



# Future Events

## 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 2018 are 7 February, 7 March, 11 April, 2 May, 6 June, 4 July, 1 August, 5 September, 3 October, 7 November, 5 December.

## EX CARERS GET TOGETHERS

*Thursday 1 February, 12 noon*

The Three Hammers pub,  
210 Watford Road, St Albans, AL2 3EA

These are informal, friendly gatherings for ex carers to have some lunch and a natter. Phone Lesley on 01923 778990 for future dates.

## THANK YOU DROP IN

*Saturday 10 March, 2-4pm*

St Stephens Church Hall, 14 Watling Street,  
St Albans, AL1 2PX

Come and join us for afternoon tea and songs from the Ricky Players.

## Future Events continued...

### BRANCH AGM

*Wednesday 4 April, 7.30pm*

Please come and join us for our AGM at:

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

The speaker will be Laura Wrangles who has been the Navigator of Care for people with Rare Neurological Diseases in Hertfordshire, for a year now. If you are living with MND and would like help with transport to the meeting, please get in touch.

## Thanks to the Noke

We would like to thank the Mercure St Albans Noke Hotel who allow us to use their hotel for our meetings.

### Contact the South Herts Branch

Lesley Ralston, Chair      01923 778 990

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