



Our new committee, elected at the AGM in April. L – R: Rosemary, John, Elinor, Jennifer, Maggie, Ben, Jenny, Alison, Carol & Lesley.

South Herts
Summer 2015
Newsletter
Our Branch Website
www.mndasouthherts.org
See us on Facebook
www.facebook.com/mndasouthherts

IN THIS ISSUE

MND
connect
08457 626262

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

Lesley Ralston	Chair	01923 778 990
Jennifer Hay	Vice Chair	01923 720 198
Alison Murdoch	Treasurer	alisonm12345@hotmail.co.uk
Maggie Coles	Secretary	01727 854 583
Rosemary Lingwood	Collection Organiser	01525 377 450
John Whale	Committee Member	01727 761 611
Ben Mansell	Committee Member	07789 796 650
Liz Pybus	Regional Care Development Advisor	08453 751 840

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.

To contact the branch email us at info@mndasouthherts.org



Helen & Glenn attend
parliamentary
reception for the
charter



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.

CHAIRS REPORT

CHAIR'S REPORT SUMMER 2015

You must be wondering what has happened to the newsletter which used to be published 6 times a year.

We have changed the format (see Spring 2015) and have a great publisher now, Jess Munday who produces the end product. I personally think the A4 new version is very user friendly and attractive and would like to keep that format. Many newsletters go out by email, so if you can also receive it by email, please let us know as it saves us a great deal of money which can be better spent elsewhere.

Unfortunately we no longer have editors with the time to spend searching for useful and interesting articles. We would also like to be able to have a 'Hints & Tips' section again, for pwMND – thank you Howard Johnson for your tips recently. If anyone has any hints & tips please get in touch with us so that we can pass on that information – any that have helped you are welcome.

South Herts Branch is becoming busier and also doing well on the fundraising front! The Ice Bucket Challenge certainly raised the profile of MND which is one of the aims of The Motor Neurone Disease Association and of course, our branch. We have two fundraising events coming up this year, which I will tell you about later.

EVENTS

GET TOGETHERS FOR PEOPLE LIVING WITH MND

August 5, September 2, October 7, November 4, December 9. 2pm.
Box Moor Trust centre, London Road, Hemel Hempstead, HP1 2RE

WALK TO D'FEET

Sunday 12th July 11am, meet at Queens Head, Church St, Chesham.

CLASSICS ON THE COMMON

Wednesday 22nd July 2-8pm, Harpenden

LADIES LUNCH

Tuesday 8th September, Chenies Manor

STREET COLLECTIONS

Harpenden 25 July

MND ASSOCIATION AGM & ANNUAL CONFERENCE

Saturday 12th September
Radisson Blu Hotel, East Midlands Airport

South Herts Branch, Summer 2015 Newsletter

We also have three new volunteers: Maggie Coles who is our new secretary, John Whale and Ben Mansell, and all three have joined the team and proved invaluable. However, we would still like to have more people to help. If you would be interested please get in touch with me. We're looking for people with IT expertise, PR/advertising, and fundraising.

Our get togethers for people with MND are going really well and are held monthly, usually on the first Wednesday of the month from 2-4pm at the Box Moor Centre in Hemel Hempstead. We get new people coming to nearly all the meetings which are VERY informal and usually noisy. We would love to meet you so do get in touch. The next one is on July 1st. In my absence please contact Jenny Fellas if you would like a chat.

So on to the events we are holding this year:

On 22nd July we have been chosen as one of 5 charities to benefit from The Harpenden Classics on the Common annual event organized by Harpenden Village Rotary Club. If you can help we need lots of people to sit or stand shaking buckets. We will also have a gazebo with tables selling craft type things and bric-a-brac. All contributions welcome!

The money collected will be divided between the charities, and the money we make on our stall we keep.

The event takes place from 2-8pm and is apparently a great day out. So if you can't help, please do come, and make sure you come to say hello to us as well.

If you would like to help I need to know your names and also your car registration number to reserve a parking space for you. Please let me know what time you could do as well. I am away from 20/6-1/7 but you can leave a message on my answerphone.

On 8th September we are holding our second Ladies Lunch at Chenies Manor near Rickmansworth. See enclosed flyer. Last year it proved a great success – the weather was spectacular as of course is Chenies Manor. At any time of the year the gardens are beautiful and Mrs MacLeod-Matthews and her staff work tirelessly to keep them in tip top condition.

Please get in touch with Rosemary Lingwood to book your place – and bring your friends. We have already had a great deal of interest and places are limited. ra.lingwood39@btinternet.com

Our collections at The Odyssey, St Albans and The Rex, Berkhamsted cinemas when the film The Theory of Everything was shown, were incredibly successful. And also the Watersmeet cinema club, Rickmansworth where we had 2 collections. We raised an amazing almost £5,500. Thank you those venues for allowing us to do the collections and all those people who gave so generously.

We were chosen by John Lewis in Watford as one of their 3 charities in January, February and March of this year and we received a cheque for £750.

We were also one of 3 charities for Waitrose instore token collection in the Rickmansworth store in May. As yet we have not been informed how much we will receive. We are very grateful to both John Lewis and Waitrose for including us once again.

Gary Phillips who is the brother of Glenn Phillips - a person living with MND, organized a Vinyl Evening at his local pub. This was held in support of Glenn and another person living with MND, Peter Walsh. They raised £650 and have requested that Glenn and Peter stipulate how they would like to spend the money. They have asked that it be used for the group who attend the get togethers which we hold. So watch this space to find out what their decision is!

Here's hoping we finally start summer soon.

Lesley Ralston

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 2015 are August 5, September 2, October 7, November 4, December 9.

CLASSICS ON THE COMMON, HARPENDEN, WEDNESDAY 22ND JULY 2 – 8pm.

Once a year, Harpenden Common comes alive for half a day with more than 1200 classic cars, other 4-wheelers, motorcycles and scooters. There you'll find a chevy Bel Air rubbing shoulders with a 1927 Trojan, and a rare 1978 Matra Bagheera with a '59 Berliot. Plus 10,000 admiring spectators. Little wonder Classics on the Common, already Britains biggest mid-week classic car show, ranks among the top events of the classics calendar.



This event is organised by the Harpenden Village Rotary Club, and last year it raised £30,000 for charity. We are one of 5 charities set to benefit this year. Come and enjoy the day and see us on our stand. Entry is free. For more information see www.classicsonthecommon.com

STREET COLLECTIONS

We are holding the following street collection and would be very grateful if you could spare an hour or two to help. Please contact Rosemary Lingwood if you can help.

Harpenden 25 July

LADIES LUNCH, CHENIES MANOR, TUESDAY 8TH SEPTEMBER



See enclosed flier for details

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
49,000.

Price £7,995

Contact Jennifer Hay 01923
720198 or

rollewisjenhay@gmail.com

THE THEORY OF EVERYTHING COLLECTIONS

There has been much mention of The Theory of Everything lately especially with Oscar wins recently. In-line with many other MND Association branches, the South Herts branch were also collecting at local cinemas which were showing the film. At South Herts we had the advantage of having two boutique cinemas, and a film club, which not only allowed us to collect after each performance but wholeheartedly supported and promoted our collections. This was demonstrated by the owner giving a speech before the performance letting the audience know there would be a collection after, and putting that in writing on the notice board.

With the Odyssey, in St Albans, and the Rex, in Berkhamsted, allowing us to collect and Mr James Hannaway the owner informing people they could donate we never missed a showing. We would be waiting outside in our tee shirts, with our buckets. This took military precision planning.

We also collected outside Watersmeet Theatre in Rickmansworth, when the local film club showed the film. The film club, run entirely by volunteers, also donated £50 to the branch. The grand total collected after the film showings came to £5,465.48. We would like to thank the cinemas, the collectors and, of course, everyone who donated.

Perhaps it is all justified as this moving story about ex St Albans School for Boys pupil Stephen Hawkin seems to bring out the most generous nature in people of South Herts.

Ben Mansell



Jennifer & Lesley at The Watersmeet, Rickmansworth.



Sian Goodwin & Lesley at The Odyssey, St Albans.

MND CHARTER DELIVERED TO DOWNING STREET



From left to right: Oliver Dowden MP, Helen, Glenn & Charlotte Hawkins.

Two people living with MND from South Herts attended this reception, Helen Lipieta and Glenn Phillips. Here is Helen's account of the day.

“Glenn and I attended the parliamentary reception for MPs at Church House Conference Centre on 16 June.

The purpose of the reception was for people living with MND, their carers and Branch volunteers to meet their local MP. As the disease is rare, the intention was to make MPs aware of the disease, the Association and what it's like to live with MND or care for someone with it. MPs were invited to help by making contact with their local Branch, attending a Branch meeting or event, or meeting in their local surgeries. It was also suggested that MPs might support individual patients if they were incurring difficulties with local services.

We were delighted that our MP for Hertsmere, in South Herts, Oliver Dowden, came to the reception. He was very friendly and approachable, keen to hear about the disease and the challenges we face in day-to-day living and getting appropriate services on time. He asked questions about the content of the MND Charter and local health and social services. He listened attentively and seemed genuinely interested in our experiences. Bearing in mind Mr Dowden is newly-elected and no doubt facing multiple demands on his time, it was great that he made time to come and meet us and, indeed, stayed with us quite a while. I felt the Branch had made a valuable link and opened up a line for communication for the future. Sally Light, Chief Executive of the MND Association spoke about handing a petition into 10 Downing Street that morning, highlighting shortfalls in care and support. Sally introduced the five-point MND Charter to address these shortfalls nationally and locally. Over 33,000 people had signed the Charter, calling for recognition of the rights of MND patients to be treated in an appropriate and timely way whatever area of the country they live in. David Setters from Surrey, who lives with MND, spoke movingly of his personal experience and his commitment to campaigning to raise awareness of the disease. Charlotte Hawkins from ITV's This Morning programme had many colleagues wiping away tears and broke down herself as she described watching, and caring for, her father until his death earlier this year. Charlotte paid tribute to the support her family received from the Association, and in particular, the comfort in knowing you are not alone. She continues to be actively involved in campaigning to raise the profile of the disease. Charlotte made time to speak to people around the conference room and joined Glenn and myself for a chat and photographs. Eric Rivers from North London made an impromptu, but unforgettable, speech using his eyegaze technology on the immeasurable value of words, not least to communicate love, and his despair in no longer being able to speak. Thank you to the Branch and everyone at meetings for giving Glenn and I the opportunity to attend a very worthwhile occasion.

NEW COMMITTEE MEMBER



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

Hi I'm Ben Mansell, I'm a husband to Judy and father of two to Phoebe 5 and Rupert 18 months. In my day job I'm CEO of a technology services company. I've always been a keen, although not necessarily good, sportsman. I spent most of my twenties and thirties playing rugby and being very involved in the rugby club in various roles, captain for a number of years and then committee member for a few more years, then came marriage and children. For those of you who've had children, you will understand that

whirlwind tends to completely take over your life for a few years. I'm now at a stage where my wife seems to have a modicum of control of that situation which has allowed me some free time, I can't spend it all on the golf course and wanted to find a charity where I could make a difference.

Why MND I hear you ask! Our family has been affected by MND for the last 21 years since my wife's uncle was first diagnosed. He has defied all convention by continuing to live life to the full and be an inspiration to us all. Clearly his and our lives have changed dramatically and mobility has deserted all but one finger which allows him to use a computer mouse and stay connected to the outside world. He continues to enjoy life, going out, enjoying fine restaurants, pubs, family events and, more importantly, good wine and great company. I also have an insight into the other side of this life and the time and effort it takes just to get out of bed and dressed every day, impossible without the fantastic carers who visit twice a day. Life hasn't been without significant scares when infection has taken place and lengthy hospital stays have literally saved his life, it's an incredible story.

So when I was looking for somewhere to spend my time and add my support something connected to MND made sense and I was put in touch with the South Herts branch.

My contribution to date has been limited as I learn about what the branch does and how it helps people, quite often for an all too short period of time, but makes a big difference on a real practical level. I'm learning about how we raise funds and the increasing awareness of MND is having a positive impact on that. MND is a truly awful disease and its indiscriminate nature seems to have touched a chord with the public, who want to support something that could affect them as much as anyone else.

The ultimate goal of course is to support National Office find a cure for this and other neurological diseases so I was pleased to learn that much of what we raise is passed to them.

So far though I have really enjoyed meeting the other committee members and learning the difference we can make by simple things like supplying an iPad to someone who is struggling with their speech, so they can again communicate with their family. It may not sound much but I can fully understand the huge

difference that would make for the whole family as they come to terms at such a devastating time. My aim is to help the branch be in a position to purchase whatever equipment is needed for whoever needs it but I still have a lot to learn first.

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.

