

## **North and East Herts Branch November Newsletter**

**A VERY MERRY CHRISTMAS TO YOU ALL**



The MND association website is: [www.mndassociation.org](http://www.mndassociation.org)

The National Office helpline is: 03457 626262

Motor Neurone Disease Association – Registered charity No. 294354

Patron: Dr Viv Lucas

## A Message from the Chair

It was a pity that we had to cancel the October meeting at Bedwell as I know some of you were looking forward to hearing all about Remap from Bruce Carr. Unfortunately the Centre had been let to an organisation for regular weekly Wednesday evening meetings and our irregular booking had been overlooked! The committee will be looking at alternatives at our next committee meeting in November. We have however booked Bedwell for the next meeting there, in January, on Wednesday the 27<sup>th</sup> January. This will be in the afternoon from 2 to 4 o'clock to avoid coming out on what could be an unpleasant winter evening. The September outing to Jordons was well supported and enjoyed by all who went and our thanks must go to Marilyn for organising the event.

We must also thank Heather for supporting the Dragon's Apprentice Scheme involving secondary schools in Welwyn Garden City and you can read more about it in this newsletter.

Also in this newsletter are details about a Gala Charity Concert at the Gordon Craig Theatre which is being organised by Iain and Keryle's son Neil on Sunday April 10<sup>th</sup>. This is a most exciting venture and will be a very enjoyable afternoon as well as raising a great deal of money for MND. So make a note of the date in your diary and get all your family and friends to support it.

The November meeting will be replaced by a Christmas lunch at the Three Horseshoes, Hooks Cross where we have met several times in the past.

This has been arranged for **Thursday 10<sup>th</sup> December at 1.30pm** The three course lunch will cost £25 per person which includes coffee and mince pie and the tip.

Those of you who would like to go should get in touch with me, as soon as possible, either by e-mail or phone **01438 488653** [g.lenderyou@gmail.com](mailto:g.lenderyou@gmail.com) so that I can make a firm booking.

Details on choice of menu etc. will be given to those interested nearer the time.

The festive season will be with us once more and on behalf of the committee I send my good wishes to you all for a happy time shared with family and friends.

Gloria

## Past Events

### Dragons Apprentice Challenge 2015

On the 22<sup>nd</sup> September I was lucky enough to represent the branch, along with Roger Widdecombe, Regional Fundraiser for East England, at the inaugural meeting of the Dragons Apprentice Challenge 2015. This is organised by Welwyn & Hatfield Borough Council who match teams of 6th formers from local schools, local business mentors and nominated charities. Each group was given £100 and their task, along with help and advice from their mentor, is to turn this into at least £1,000 by February. All the money raised will then be donated their charity. It really feels like a win-win scenario for all involved.



The evening consisted of introductions all round, initial discussions within the teams, a light-hearted construction challenge and an attractive buffet. MNDA was matched with a team from Monk's Walk School chosen by Gary Moore, A Level Business Studies Teacher and their mentor is Paul Haynes, Manager of the Howard Centre who nominated MNDA in memory of his mother-in-law, Margaret Holt, who died of MND last year. I met Paul, Gary and some of the students involved, Gary is clearly an enthusiastic teacher and motivator and Paul brings a wealth of knowledge, expertise and contacts to the table.

Two weeks later I attended a meeting at the school and met the nine students on our team. They are all very keen to involve the charity in the project and make their business plan relevant to MND.



Their initial plans are to hold a collection in the Howards Centre on Black Friday (27<sup>th</sup> November) which should boost their funds to finance larger projects. They are also planning to hold a Year 7 Christmas Disco before the end of term and they have already raised around £43 just from speaking to parents about the project at recent school Open evening. I have so far organised MNDA T-shirts, collection tins and balloons! I think this is a really exciting and worthwhile project and I am really looking forward to reporting back in March on what they have achieved.

## **Jordans Mill**

On Wednesday 30<sup>th</sup> September we had a nice gathering of our members at Jordans Mill for a Cream Tea in the Riverside Cafe. A really nice venue and well worth a visit. 14 members and friends attended that afternoon, and 4 of us also did the Guided visit of the Mill. This was particularly interesting, telling us the history of the Mill and its background, being a family run concern. We learned that Holme Mill was one of 6,500 watermills listed in the 1086 Domesday Book. We were able to see the Victorian machinery in action which was amazing. The volunteers giving us the information made it really interesting and certainly well worth including in our visit to Jordans. The gardens were also well worth a visit too. Altogether a very enjoyable afternoon for everyone.

## **Our Association Visitors Development Day – 7<sup>th</sup> October 2015**

Attending were Lesley Beaven, Chris Carter and Maria Watson . Our day started with our RCDA, Liz Pybus introducing us to her new boss, John Gillies, Regional Delivery Manager East. John gave us a little introduction about himself and what he had been involved in prior to joining the MNDA Association. He then went on to outline new projects in the pipeline:

Recruiting and training new AV's and a new AV support framework

Supporting the branches. John plans to visit each branch in his area.

There is a Benefits Navigator project piloting in Manchester. If successful will roll out across the country and also a new data entry project

Then came MND AND COMMUNICATION presented by Victoria Edwards, Specialist Speech and Language Therapist from Addenbrookes Hospital. This consisted of a review of high and low tech equipment and the new specialist services . The hospital is now in the process of setting up the new hub to bring together a multi-disciplinary team made up of OTs , SALTs , clinical scientists etc from 6 surrounding counties. It is planned for January 2016 .

In the afternoon session, Sara Murray ,External Compassion Fatigue Facilitator and Trainer talked about how we can protect ourselves and not burn out. We talked about our support teams like other AV's, our RCDA and managing how we cope with visiting people living with MND and their families .We enjoyed our day and it was good meeting our fellow AV's.

Lesley Beaven AV for North and East Herts.

## **24 Hour sponsored silence for MNDA – Many thanks to Jude**

Following the success of last years' challenge The Motor Neurone Disease association decided to make this years' fund raising challenge a sponsored silence. Last year they did the ice bucket challenge to simulate the shattering feeling and freezing of nerves that go with the disease. This year to imitate the difficulties of not being able to speak or being understood properly, the chosen subject was silence. You could do any amount of time you wanted, from minutes to hours. I chose 24 hours. I love talking and it was obviously going to be a difficult challenge for me. I decided to involve mum as it was in memory of Dad and I also needed somebody to keep me in check! I also decided that as a nurse I could not go to work, but that I had to do things that

involved interaction with people. In the morning my mum came in and clapped her hands to wake me up, she also wrote things down. I wrote a note saying you can talk you know. However I did find it easier to respond none verbally when she did write or not talk. This would not be a problem if I really could not talk. I spent the morning doing paperwork, and we then decided to go out to Wrest Park for walk and afternoon tea. I was to communicate getting in and buying food. I had a small card in my pocket to explain what I was doing, but only used to explain if somebody looked at me oddly and could understand. We went to Prezzo for a meal, which again I ordered and then lastly I met up with a group of friends at an AA meeting. I had to ask the chair to announce it as people knew me so well they would think I was very rude not answering.

The day went well. Of course no real problem when at home as I just got my head down and was not distracted by talking etc. At Wrest park I needed to show my card to a complete stranger, I will explain that below. People were in the main helpful and I did not feel out of place. In Prezzo, the poor waiter had to ask me to re write my order and in the AA meeting I found it incredibly hard not to just say hello.

It was the mental issues that were the most difficult things. At Wrest Park a man was telling mum how to get round a hill an easier way. He looked at me like I was very unhelpful. I showed him the card and he smiled and donated. I didn't look people in the eye or smile much as I knew this would get a verbal response I would have to ignore so it was easier to just not interact in any way. I felt left out of conversations. Writing things down, phone speech apps etc take longer and you cannot easily express emotion, humour etc.

All in all it was a very worthwhile experience without even the bonus of raising money! In total I managed to raise £566.34. In memory of my Dad Ernest Lender you and all those suffering or who have suffered from MND.

Jude Lenderou

Many thanks again to Carol Hardy who is still collecting money for us from her stall at the Oval Community Centre in May – well done Carol

Thanks also to Val Bateman from U3A, the Broxbourne walkers group raised £65.50 over 3 months from their monthly walks. The University of the Third Age movement is a unique and exciting organising which provides, through its U3A members, life-enhancing and life-changing opportunities. Retired and semi-retired people come together and learn together, not for gratification but for its own reward: the sheer joy of discovery! Members share their skills and life experiences: the learners teach and the teachers learn, and there is no distinction between them.

## **Wheelchair Service**

From the 1<sup>st</sup> November, Hertfordshire Equipment Service will be ending the current arrangements for the repair, delivery and collection part of the Hertfordshire Wheelchair Service. This service will be provided by Millbrook Healthcare 2 Maxted Court Maxted Road Hemel Hempstead HP2 7BL  
0333 2340303 – [hertswcs@millbrookhealthcare.co.uk](mailto:hertswcs@millbrookhealthcare.co.uk)

## DATE FOR YOUR DIARY

### **STAR CAST CHARITY GALA in aid of MND 10th April 2016 Gordon Craig Theatre, Stevenage.**

A very special date for your diary! Sons of Stotfold MND sufferer Iain Rutherford are producing a star studded Charity Gala in aid of Motor Neurone Disease. Neil and Carl Rutherford have worked in professional theatre for over 30 years, working on West End Musicals and international productions on Broadway and at the Sydney Opera House and all profits will go towards Motor Neurone Disease funds.

The Gala will be at the Gordon Craig Theatre in Stevenage on Sunday 10th April 2016 at 7.00pm, hosted by 'Get Me Out of Here's King of the Jungle' Christopher Biggins and Stevenage Panto favourite Paul Laidlaw, and will star West End and TV stars including Claire Sweeney, Strictly Come Dancing's Tom Chambers, Downton Abbey's Amy Nuttall and leading cast members of West End Musicals including Wicked, Guys and Dolls, West Side Story, Kinky Boots and the Royal Shakespeare Company. There will be an onstage orchestra and a choir of 30 local singers. The programme will consist of songs from the musicals and entertainment from further special guest stars to be announced. All artists are providing their services for free and are subject to availability.

Prices are £31 and £21 and are on sale from the Gordon Craig Theatre. Tickets available at [https://www.gordon-craig-tickets.co.uk/show\\_events\\_list.asp?shcode=5590](https://www.gordon-craig-tickets.co.uk/show_events_list.asp?shcode=5590) or phone 01438 363200. Disabled bookings should phone or email [boxoffice@stevenage-leisure.co.uk](mailto:boxoffice@stevenage-leisure.co.uk)

### **POEM COMPETITION**

Do you have a hidden artistic and poetic side? Suffers and those affected by MND have a wonderful opportunity to voice their experiences by writing a poem for a new Poem Competition. Even if you've never put pen to paper, there is a budding poet in everyone, particularly when this subject is so personal and emotional to all of us. The winning poems will be performed by leading actors from the Royal Shakespeare Company at the MND Charity Gala on 10th April at the Gordon Craig Theatre. (See further article in this magazine)

If you would like to submit a poem about how MND has affected you or your family, please send the poem to [Neil@neilrutherford.com](mailto:Neil@neilrutherford.com). Poems should be no more than a page of A4 and can be upbeat about the positive love, commitment, care and support you receive from all those in your life or heartfelt about the challenging problems you face. The choice, content, style and subject is all your own choice, so long as it relates to your experiences of MND. All poems received will be acknowledged and copyright will be retained by the poet. Closing date for Submissions is 30th January 2016. The winning poets will be informed by the end of February.

We look forward to receiving your creative, wonderful poems.

## FUTURE MEETINGS AND EVENTS FOR YOUR DIARY

December Thursday 10th 1.30pm	Christmas Lunch at The Three Horseshoes Hooks Cross Three course meal £25
January Wednesday 27th 2pm	Afternoon Tea at Bedwell 2pm–4pm Speaker – John Gillies – Regional Delivery Manager East
February Wednesday 24th	Lunch to be arranged
March Wednesday 30th	To be arranged
April Sunday 10 <sup>th</sup> 7.00pm	Charity Gala Concert Gordon Craig Theatre
April Wednesday 27th	A G M

Bedwell Community Centre  
Bedwell Crescent  
Stevenage  
SG1 1NA

Bedwell meetings are the last Wednesday of the month at 7.30pm

## BRANCH MANAGEMENT COMMITTEE

### OFFICERS

#### CHAIRMAN

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### ASSOCIATION VISITORS

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### THE MND NORTH HERTS WEBSITE

[www.mnd.n-herts.freeuk.com](http://www.mnd.n-herts.freeuk.com)

### THE MND HELPLINE – NEW CONTACT NUMBER

Tel: 03457 626262

All calls are charged at local rates. The hours of opening are:-  
Monday - Friday 9.00 a.m. - 5.30 p.m. and 7.00 p.m. - 10.30 p.m.  
Saturday, Sunday & Bank Holidays: 10.00 a.m. - 6.00 p.m.