

Friday 18th February 2pm - Meet and Greet - Lincoln

Join us at **St Barnabas Day Centre, Hawthorn Rd** for a very special occasion with our guest speaker **Karl McCartney JP MP**. Karl was elected as the MP for Lincoln in May 2010 and he will talk about his experiences as a newly elected MP at Westminster.

There will be a question and answer session where you will have the opportunity to raise your concerns with your MP.

Tea and Refreshments



Friday 18th March 2pm - Meet and Greet Boston

We have a change of venue for our meeting on Friday 18th March with a visit to **Johnson Garden Centre, Wainfleet Road, Boston**. We meet in the restaurant at 2pm for a talk by one of the expert Johnsons staff followed by Tea and Cakes. In addition to a huge selection of seasonal plants and shrubs in the garden section, there is a fine food store filled with goodies from local suppliers and the market place containing gifts cards, outdoor clothing and garden equipment. The garden centre is situated on the A52 Skegness road about 1 mile from the Pilgrim hospital.



Friday 15th April 2pm - Annual General Meeting - Lincoln

Our annual general meeting is a chance for members and health professionals to hear what we have achieved over the past year and our plans for the future. Our guest speaker this year is **Dr Brian Dickie**, Director of research at the MND Association and the organiser of the International ALS/MND conference. He will update us on all the latest research into the causes and treatment of MND.



Lincolnshire Branch "Tea on the Terrace"

Wednesday 18th May 2pm - 4pm
Petwood Hotel, Woodhall Spa

Join us for our spring event with our now traditional "Tea on the Terrace" at the Petwood Hotel Woodhall Spa. This year we are delighted to have Dr Kirstine Knox, Chief Executive of the MND Association as our special guest. Kirstine has now been in post for 5 years and the charity has made huge strides under her leadership. We will be sending out details with a booking form with the march newsletter.



LINCOLN meetings are held at the St Barnabas Day, Centre, Hawthorn Road
BOSTON meetings at the Methodist Centenary Church, Red Lion St.



Maps with directions to St Barnabas and the Centenary Church may be found on the Branch website www.mndlincs.org.uk or by post from Gordon Hickmore

KARL McCARTNEY JP MP
LINCOLNSHIRE BRANCH PATRON



We are delighted to announce that **Karl McCartney JP MP** has agreed to be a patron of the Lincolnshire Branch. He was elected as the Conservative Member of Parliament for Lincoln in May 2010. Karl lives in Lincoln with his family and as a local man he is keen to "put Lincoln first" and listen to the voice of his constituents. He is involved with a number of local organisations, charities and voluntary sector groups and we hope that with his support, it will ensure that our MND patients and carers continue to receive the best possible care during the restructuring of the health and social services.

Karl has agreed to be our guest speaker at our next **Meet and Greet** to be held at the St Barnabas Day Centre, Hawthorn Rd Lincoln on **Friday 18th February at 2pm**. He will talk about his experiences as a "New Boy at Westminster". Do make a note in your diary and come along and enjoy what we are sure will be an entertaining afternoon with the opportunity to ask questions of your MP!



FIGHTING MOTOR NEURONE DISEASE

Our Thumbs Up symbol represents David Niven's last defiant gesture. It remains our symbol of hope.

THE VIEW FROM THE CHAIR

Dear Friends,

We start the new year with the good news that Karl McCartney MP for Lincoln has kindly agreed to be the patron of the Lincolnshire Branch. Karl was elected as MP for Lincoln in the May elections and as a local man he is very keen to be involved with local charities and organisations. We know that 2011 will hold many new challenges and the Government's vision of a Big Society means there will be more competition than ever before for us to stand out from the crowd. Karl's support will help us build momentum to meet the challenges ahead. Karl has also agreed to be our guest speaker at our next meet and greet at St Barnabas on 18th Feb (he will be speaking about his experiences as a new boy at Westminster) so do come along and enjoy an interesting afternoon!

Over the past few years the Lincolnshire branch has done much to raise awareness of the disease in the county and we have been very successful in gaining the support of many groups and individuals to raise funds to support all our MND patients and carers. However the role of the Branch is evolving and with the proposed changes to the health service structure, we have got to put our heads above the parapet so we can influence the quality of care for the patients we support. At present health care is commissioned within Lincolnshire by a single unit, the Lincolnshire Primary Care Trust. In 2013 this will be replaced by 7 independent GP consortia, all of which will have their own priorities for the care and treatment of patients. MND is a minority disease and we must ensure that our voice is heard so we don't end up with a postcode lottery within the county. This is chance or you to get involved so don't hold back and join the MND campaigners net work which you will see on the page opposite.

As you will see from the photos on our centre spread, we had some wonderful social and fundraising events to end a very successful year. The Halloween ride-in organised by Tara and Leigh Kemp really took off and thanks to personal donations and business sponsorships raised a fantastic £1850. The Thumbprint Ball was a sell out and Sarah and Kevin Hill will be presenting us with a cheque for £1000 from the event. The RAF Shades of Blue band concert in November was again a sell out and raised over £700 which will be shared with the RAF Association. With the bitter cold and heavy snow, we wondered if we should cancel the Christmas Lunch but thankfully the weather improved and 57 members and friends enjoyed a wonderful meal at the Petwood Hotel. Our thanks also to the employees of Taylors garages in Boston who raised £137 in sponsorship in lieu of sending Christmas cards and to the many private donations we received over Christmas and the new year. These donations make up a substantial part of our income and enable us to provide equipment and support for patients which otherwise would not be available through the health services.

We have an interesting programme of events planned for 2011 with our meet and greet at St Barnabas in February, A visit to Johnson's Garden Centre in Boston in March and the AGM in April with guest speaker Brian Dickie. At spring event, Tea on the Terrace" at the Petwood in May, Kirstine Knox, the MNDA chief executive will be our special guest. We have lots of collections organised in June at Tesco stores during awareness week so we will be seeking your help to hold the tins! Last year we raised over £2500 from store collections despite the recession. We are planning a summer outing in August and we would welcome your suggestions for the venue - currently Grimsthorpe castle looks promising. We have many other events planned and we will keep you updated on all the latest news in the Spring edition of the Newsletter.

Kind regards
Gordon Hickmore

We do try to keep our mailing list updated but there are bound to be changes which go unrecorded. Please accept our apologies. If you no longer wish to receive the Newsletter or your personal details have changed, please inform Gordon Hickmore 01522 526898 or email mndlincs@mndlincs.org.uk

NAME THE ROCKING HORSE COMPETITION



The Winner of the "Guess My Name" competition for the Rocking Horse is Mrs D Castle of Scunthorpe who chose the name "Pegasus" for the horse. 5 people also chose Pegasus but Mrs Castle's entry was the first out of the hat.

We had over 900 entries which raised £462 for branch funds. Mr and Mrs Castle kindly donated the Rocking Horse which was specially made for us by John Pye, to the children's ward at the Pilgrim Hospital, Boston.

We presented the horse to the Ward on Wednesday 22 December.

THE TOMBOLA QUEEN

Mary Pick, our Tombola Queen has run her Tombola stall at village fetes, Boston market and the steam rally starting in April, through summer months come wet or fine, and ending her vigil for the year on a cold and frosty weekend in December at Springfields. She has raised a staggering £1352 this year for branch funds. Takings have varied but over the 2 days at Springfields she raised £452! ...Mary was award her Silver Association badge this year and at the age of 81 she is still going for Gold!



Branch Contacts

Sue 01522 526898 for Lincoln area

Ann 01205 365960 for Boston area

Branch Officers 2010 -2011

Chairman - Gordon Hickmore 01522 526898

Secretary - Liz Anderson 01406 490709

Treasurer - Daphne Oxford 01526 860848

AV Coordinator - Keith Bray 01507 343761

Web sites:

MND Association
Lincolnshire Branch
Email

www.mndassociation.org
www.mndlincs.org.uk
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Other Useful Contacts

National Office 01604 250505

MND Connect 08457 626262

Regional Care Adviser

Jane Connell 01636 642814

Benefits Enquiry Line

0800 882200

Unveiling the MND online forum

The MNDA has launched a new online forum – a safe place for people affected by MND to share experiences and support each other with the challenges of living with the disease.

The forum - <http://forum.mndassociation.org> - went live on 8 December and has been developed as a direct response to requests from people living with MND who recognise the benefits online forums bring. It will offer an alternative way of people living with MND and their carers seeking support and interacting with each other without having to leave their home, reducing the isolation MND can bring. We are confident our new forum will provide an important addition to our website and will complement our MND Connect advisory telephone and email services and the information and support provided by you locally. It will be co-ordinated by Robyn Copley- Hirst in our MND Connect team, who will regularly visit the site during the day and evening to ensure the content is appropriate. While volunteers are not encouraged to post on the site, other than those with MND and carers, you will be able to view the content enabling you to get a feel for issues that are important to those living with the disease. The forum will also help influence the development of our future care information.

Kaye Stevens, Care Information Coordinator said: “The online forum is primarily a key communication tool for people affected by MND, but will also become an important influence for the development of care information. It will help to highlight key areas of interest and concern, which will feed into the continuous improvement and expansion of our care information provision. “It will be very interesting to see what trends emerge and how we might be able to respond with more immediacy as an organisation - both directly and through our future publications.” We do hope you will encourage those affected by MND in your area to visit the forum.

Celebration Fundraising

IF YOU are planning to celebrate a special occasion — congratulations! Would you also like to use your special occasion to raise funds for the MND Association? People are increasingly adopting this method of fundraising, which is why we have now developed a ‘give in celebration’ section on our website, designed to provide help and guidance for those wishing to organise a celebration fundraising event.

Whether it’s a special birthday, landmark anniversary or perhaps you are getting married and would like donations in lieu of wedding gifts, we can help, with special gift envelopes, easy to set up online donation/event pages plus colourful balloons and T shirts etc if required.

Just visit our website for more details:

www.mndassociation.org/get_involved/donations/give_in_celebration



Phone and Print Cartridge Recycling



Have you an old mobile phone stuffed in a drawer or get a twinge on conscience when you discard your empty print cartridges in the bin? The MNDA will now pay £3.50 for a mobile phone and 70p for each print cartridge or laser toner which will be credited to the Lincolnshire branch. Contact Gordon 01522 526898 or email recycle@mndlincs.org.uk for your specially coded bag!

Adapting to a new political agenda

THE Government wants more local-level decision-making about public services, including health and social care. Our campaigning and influencing activity needs to adapt to the new political agenda – and we all have a part to play in making this happen.....

INTRODUCING THE MND CAMPAIGNERS NETWORK

WE may have a tough fight ahead to protect Services under threat due to increasing financial pressure – services that people with MND rely on. However, it’s not just about maintaining existing services, we also need to campaign hard to ensure these are improved and lobby for new services for people with MND where appropriate. This will be difficult in a time of instability and financial austerity in the NHS. So it’s more important now than ever before, that we have a strong voice and are able to respond to these challenges. That’s why in 2011, the Association will be launching a new MND Campaigners Network. We will be offering members of the MND Campaigners Network the support and skills to campaign locally to make changes happen.

*Together
we can make a
difference*

The Government Health and Social Care Bill, published on Wednesday 19th January, sets out the framework for the the Health services. Strategic Health Authorities and Primary Care Trust will be abolished, and replaced by GP consortia by 2013. At present, Lincolnshire is served by a single PCT based in Lincoln and commissions services for 735,000 people. There are 102 GP practices which have combined into 7 consortia to replace the single PCT.

While the aim of the bill is to reduce bureaucracy and improve services by transferring budget responsibility to the 7 GP Consortia, it is difficult to see how this can be done more efficiently particularly when the government is seeking £20 billion savings in the health budget. We are fortunate to have a model standard of care for MND patients in Lincolnshire so we must ensure that this is not diluted and we do not have a post code lottery with variations in the standard of care within the county.

It is 2 years before the transfer so we need your help to ensure that our MND patients are not disadvantaged by the changes. Please get involved and help us protect our services!

Raj Johal,
National Campaigns
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Stop Press!

A recent auction of cigarette cards donated by a member and sold on line on Ebay raised a total of £163 for Branch funds. Earlier a dealer had offered just £25 for the sets. Have you an unusual item you would like to donate which we can sell on ebay? Smaller items which are easy to pack and post are best. Contact Gordon for more details (See contact list)

