

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. Unfortunately **Dr Brian Dickie** has a trustees meeting but he is replaced by Belinda Cupid Head of Research at the MND. She will update us on all the latest research into the causes and treatment of MND. The talk will be followed by the formalities of the AGM including the election of officers and the presentation of the accounts for 2010-11. Tea and refreshments are provided.



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. The cost of the meal is £12.50 - MND patients and carers are free. Please see the enclosed invitation for details.



Friday 17th June - Meet and Greet Lincoln - St Barnabas Day Centre 2pm

Join us for our June Meet and Greet at St Barnabas day Centre Hawthorn Rd for our monthly get together. Our guest speaker is Mark Keal of Trading Standards in Lincoln. Mark will tell us about the work of trading standards which covers everything from weights and measures, market trading, doorstep selling and a host of other responsibilities. He will no doubt have some horror stories to tell about some of the methods that rogues use to part you from your money! Tea and refreshments provided.

June 9th, 17/18th, 23rd, 30th - Collection days at Tesco Stores

During MND awareness week in June we have been granted collection days at the Tesco stores in Boston, Sleaford and Lincoln. We need volunteers to help at all the stores so if you can spend a couple of hours at any of the stores please ring Don 01205 367614 for Boston or Sue 01522 526898 for Lincoln and Sleaford.



Sunday 3rd July - A day at the Races!

Once again we are the chosen charity for the Don Noble Race day at Market Rasen on Sunday 3rd July. Join us for a day at the races and help us with our collection - In 2010 we raised a magnificent sum of £845 from the collection as racegoers left with their winnings. First race 2pm last race 5.15pm. Tickets for entry to the Tattersall enclosure will be £10 (£5 if you help with the collection) contact gordonhickmore@mndlincs.org.uk or reserve your tickets by returning the enclosed booking form.



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

THE THUMBPRINT BALL RAISES £1000



**PRESENTATION BY SARAH
OF £1000.00 FROM THE
ANNUAL MND BALL**

The Annual Thumbprint Ball held at the Boston Golf Club in November raised the magnificent sum of £1000 for branch funds. The ball organised by Sarah and Kevin Hill in memory of Sarah's Mum Carol, was a sell out with over 100 people attending. The cheque was presented to her father Rob Biggs, at the March meeting of the Branch at Johnsons Garden Centre in Boston.

The Garden Centre proved a very popular venue and we hope to arrange further meetings at Johnsons during the summer!



We never lose hope. We strive to find a cure for MND and to support everyone affected by this devastating disease

THE VIEW FROM THE CHAIR

Dear Friends,

After a relatively quiet period during the winter months, the committee is gearing up for another busy year starting with our AGM on 15th April. While the AGM report looks at our performance in 2010 it is very much the time when we look forward to the challenges we will have to meet in 2011 and beyond. Once again I am pleased to report that the branch is in a strong financial position having received substantial income from personal donations, our fundraising activities and sponsorship. It has enabled us to meet all our commitments to patients and carers and we pride ourselves that we will make a decision on a funding request within 24 hours. Speed is the essence as a patient cannot be left waiting for equipment or help when the need is immediate. Close liaison with the Outreach Team and the health services ensures a rapid response to all requests. Great responsibility falls upon the Treasurer to keep the accounts in order and prepare them for the annual audit so it is with sadness that I have to record that Daphne Oxford will be standing down after 6 years in post. Liz Anderson will be taking over the role which leaves a vacancy for a secretary - so please see details below!

As you will see from the events diary, Brian Dickie has Trustees meeting on 15 April but I am delighted to say that Belinda Cupid, Head of Research at the MNDA has agreed to be our guest speaker. Belinda is at the forefront of MND research, organising the scientific programme for the MND/ALS international conference and the development of clinical trials and the MND database.

Looking ahead to our events during the summer months, we have our "Tea on the Terrace" event at the Petwood on 18th May which will be attend by our very special guest, Kirstine Knox, chief Executive of the MND Association. The Petwood is a magnificent venue so please come along and enjoy a wonderful afternoon. June is a very busy month with collections during awareness week at Tesco stores in Lincoln, Boston and Sleaford and on 3rd July we are at the races as the chosen charity for the Don Noble Race day at Market Rasen. In July we have a change of venue for our Boston Meet and Greet to the Supreme Inn at Bicker where we will have tea and cakes and a guest speaker. More details in the July newsletter.

Finally we have a very busy year ahead and your committee will be working hard to ensure we continue to provide that extra care to help all those affected by MND in Lincolnshire.

*Kind regards
Gordon Hickmore*

Stop Press - We need a Secretary!

Sadly Daphne Oxford is standing down as Branch Treasurer. She has done a fantastic job over the 6 years she has been in post. She will be replaced by Liz Anderson so we need a volunteer to replace Liz as secretary on the committee! Can you help? The duties are not onerous but the post is vital to the running of the Lincolnshire branch. Duties include taking the minutes of our bi-monthly committee meetings in Boston, corresponding with MNDA national office, liaising with health professionals and dealing with inquiries from our members. On average the duties will only take 2-4 hours a week of your time. IT skills are essential as we cover the whole of Lincolnshire and much of the day to day administration of the Branch is completed by email. It is an honorary position but we do pay travel expenses to meetings and events.

If you would like to learn more about the post please ring Liz on 01406 490709 or Gordon 01522 526898

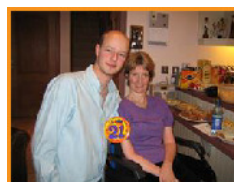
We do try to keep our mailing list updated but there are bound to be changes which go unrecorded. Please accept our apologies. If you no longer wish to receive the Newsletter or your personal details have changed, please inform Gordon Hickmore 01522 526898 or email mndlincs@mndlincs.org.uk

MNDA - PMA/PLS Support Group

Have you been diagnosed with PMA/PLS? If so please read on.....Are you interested in joining our email-based support group? We have a well-established email based support group, where people living with rarer forms of MND have an opportunity to link up with others and have an opportunity to contribute to the Experiences of PMA/PLS pages. Whilst most members are from the UK, there are some from other countries, so becoming international. If you are interested in joining the support group please e-mail your details to: care@mndassociation.org

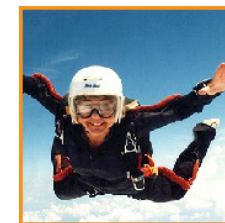
MNDA Online forum

The MNDA online forum is going from strength to strength, providing a safe place for those affected by MND to share experiences and support each other with the challenges of living with the disease. If you would like to join the forum go to: <http://forum.mndassociation.org>



SPONSOR LAURA ON HER SKYDIVE CHALLENGE!!

<http://www.justgiving.com/Laura-Tomlinson0>



Laura's Mum, Patricia Stratford, died of MND 6 years ago. Since that time, Laura and her brother Mark, Tricia's sister Kathy, together with friends and holidaymakers at Tomlinsons Caravan Park, Chapel St Leonards, have raised many thousands of pounds for the Lincolnshire branch. This year Laura's challenge is to raise £2000 through a sponsored skydive. Laura plans to complete the 10,000ft dive in Nottingham on 17th May. You can support Laura on her challenge by visiting the "Just Giving" website and making your donation which is then gift aided or contact Tomlinsons tel 01754 872241 for more details.

Branch Contacts

Sue 01522 526898 for Lincoln area
Ann 01205 365960 for Boston area

Branch Officers 2010 -2011

Chairman - Gordon Hickmore 01522 526898
Secretary - Position Vacant
Treasurer - Liz Anderson 01406 490709
AV Coordinator - Keith Bray 01507 343761

Web sites: MND Association
Lincolnshire Branch
Email

Other Useful Contacts

National Office 01604 250505
MND Connect 08457 626262

Regional Care Adviser

Jane Connell 01636 642814
Benefits Enquiry Line
0800 882200

www.mndassociation.org
www.mndlincs.org.uk
mndlincs@mndlincs.org.uk

PATRICK THE INCURABLE OPTIMIST

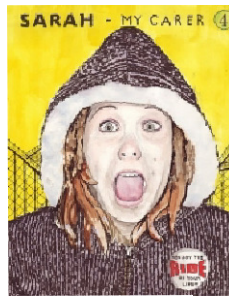
It has been a year now since this all started, since I decided to paint one hundred portraits before I die. I've just finished no. 17, and whether I will ever make it to 100... well we shall just have to see. We've decided to mark a year of incurable optimism with an exhibition in April, at least it started as an exhibition, soon it was two exhibitions, then four, and at the latest count there are going to be at least seven, all starting in April!

OVER the past year Patrick Joyce has been painting portraits of incurable optimists to help raise awareness of MND. His portraits highlight the amazing people who make up the MND Association community.

From April exhibitions will be held in a variety of venues including a café, a school, an art gallery and even a football ground! Confirmed exhibitors so far range from volunteers and people personally affected by the disease, to those who had never heard of MND before they saw the billboard posters or started following Patrick on facebook.

If you would like to hold your own exhibition of Patrick's portraits please contact Tina Downs tina.downs@mndassociation.org who will send you all the materials you will need to put on your own exhibition.

Patrick has joined forces with his neurologist and neuroscientist, Dr Martin Turner, to hold an exhibition entitled Incurable Optimism— two different ways of fighting presenting their two very different approaches to fighting MND in the inspirational exhibition. The exhibition is being held at Oxford University Museum of Natural History from 31 March – 6 May.



Tillie Baker's Home of Good Food Welcomes You

Curtis Walk (off Market Place), Gainsborough DN21 2BX Tel: 01427 614111
 Serving Delicious Home Made Cakes, Soups, Sandwiches, Paninis, & much more. Freshly Ground Fairtrade Coffee. Friendly Relaxing Atmosphere. Fully licensed, free wireless internet .
Currently showing; Portrait exhibition - the work of Patrick Joyce; An incurable optimist. Entrance free. Donations to the MND Association.
For opening times and bookings go to www.tilliebaker.com

800 to take part in clinical trial

A LARGE clinical trial to test the safety and effectiveness of a new drug called dexpramipexole (formerly known as KNS760704) is expected to get underway within the next few months.

Six centres in England will be recruiting participants with MND who experienced their first symptoms less than two years before the start of the trial. The 18-month trial, also known as the EMPOWER study, is being organised by a pharmaceutical company called Biogen Idec and will involve over 800 people with MND in total, recruited from ten countries across the globe. The six trial centres in England will be located in Newcastle-upon-Tyne, Sheffield, Liverpool, Birmingham, Oxford and London.

Although it is not expected to begin until mid-2011, awareness of the trial is already quite high among people affected by MND as it is being discussed on a number of internet forums.

Recruitment for the trial has not yet started and we do not yet have contact

names at the six UK centres. We know that the trial will only be open to people who have had their symptoms for less than two years before starting on the trial but other than that we do not have details of the criteria that people will need to meet in order to take part. However, as soon as we have managed to get hold of all of these details we will produce an information sheet for people affected by MND. This will be available to order from MND Connect or to download from our website at: www.mndassociation.org/clinicaltrials . where you can also find background information on the drug.

The research development team at national office would be happy to answer any questions and can be contacted on 01604 611880 or at research@mndassociation.org

People who are interested in taking part in the trial should also discuss it with their neurologist, or get in touch directly with one of the trial centres, once contact details have been made available.

PLANNING A HOLIDAY?

Exceptional holiday accommodation for people with disabilities



Located in the heart of beautiful rural Dorset in the peaceful hamlet of Woolland, Ellwood Cottages are outstanding conversions of three traditionally built barns, in a courtyard setting. Named after Dorset writers Hardy, Barnes and Blyton, the wheelchair-accessible cottages have been lovingly restored to provide comfortable, tastefully furnished, year-round, single storey self catering holiday accommodation for disabled people, their families, friends and carers.

The Lincolnshire Branch will provide a grant towards the cost of your holiday at Ellwood Cottages for MND patients and carers

For more details Tel John and Ann Heath - 01258 818196 www.ellwoodcottages.co.uk

