Join us on 5th April 2014 for the Branch AGM and Lunch with Dr Brian Dickie

Inside
- New Year Event: Oxford research moving onwards...
- Notes from an Oxford MND Campaigner
- Local fundraising and awareness
- Orpheus Choir raise voices for MND research
New Year Event
Oxford research moving onwards...

Once again the progress being made in research proved a popular topic for our New Year event in January. Thirty five people came to hear Professor Kevin Talbot, who specialises in molecular and cellular biology and stem cell research in particular. He told us that both he and Dr Turner, in his biomarker study, were interested in finding out what happens early on before the development of symptoms of MND. In the last ten years there have been more encouraging steps in their research which has increased knowledge and should help to speed up diagnosis.

Neuroscientists now know that MND has multiple causes and is a spectrum of conditions. Genetic factors can play a part in sporadic MND though only 5% of those with the disease have the familial version directly inherited through a single gene in a predictable way. As usual this provoked some interesting questions from the audience which Professor Talbot clarified in his answers.

There has also been progress in the understanding of fronto-temporal dementia, which affects a number of people with the disease. It is beneficial to recognise symptoms particularly to support those in a caring role.

Different models of the disease can be studied, not just the mouse and fruit fly as in years gone by. In one clip from his presentation we watched the unsteady progress of a mouse affected by MND on a ‘catwalk’! However it is now possible to grow motor neuron cells in the laboratory that have the TDP43 protein which accumulates when MND develops. This means the cells can be screened and some drug companies are very interested in this development, though effective drug treatment is still some way off.
Jenny Rolfe, Occupational Therapist on the Oxford Care Centre team gave us an interesting update from the Allied Health Professionals forum which is held alongside the scientific programme at the recent three day MND International Symposium in Milan.

- Latest information on respiratory issues including instituting non-invasive ventilation at the optimum time, as well as potential improvements in quick release masks to make users more comfortable (coming soon to Oxford clinic patients we hope!)
- Minimising risk in PEG procedures. Mel Lord from the Oxford team presented her findings at the Milan Symposium
- The development of much needed guidelines to help inform physiotherapists, OTs and others involved with care of MND patients
- Updates on IT and other equipment available to be used in support of people with MND. This included providing specialised powered wheelchairs for people with progressive neurological conditions, which can be adapted for ongoing use

There was much interest at our meeting in the cuddle chair – a double riser recliner that Jenny told us about enabling adults and children to share seating with someone disabled. Jenny will be asking the Association, who provide riser recliners on loan, to consider purchasing some of these.

The Oxford team found this Symposium as stimulating as ever and have identified key points to follow up. Lynda summed up our feelings of admiration and respect for all that they do and thanked everyone for their interest and excellent questions. There was time left to enjoy Lynda’s homemade cake while getting to know those who were there for the first time and chatting to old friends which is an important part of every meeting we hold.

We never lose hope. We strive to find a cure for MND, and to support everyone affected by this devastating disease.
The Oxfordshire Branch AGM and Lunch

Saturday 5th April 2014
Registration 11.45am Holiday Inn, Peartree Roundabout, Oxford.

More information
Members are encouraged to send nominations for the committee. Forms are available on request from the secretary and suggestions or points for discussion are welcome by 22nd March.

Speaker after Lunch at 2pm Brian Dickie MND Association Director of Research Development.

For replies or further details contact Lesley Ogden on 01235 850372 or e mail lao.ogden@googlemail.com

Other 2014 dates for your diary

Garden centre visit
4th June 2014
Venue: Burford
Time: 14.00

Helpful organisations forum
July 2014
Venue: Oxford
Time: 13.45
Come and find out what is on offer

Branch Walk
11th October 2014
Venue: Blenheim Park
Time: 13.00
Annual walk around the grounds of Blenheim Palace.

MND Connect is available 9am to 5pm and 7pm to 10.30pm Mondays to Fridays. Calls charged at local rate.

08457 626 262
Mark Stone: Notes from an Oxford MND Campaigner

Looking forwards to 2014...

Welcome to a new column from a local MND ‘campaigner’. I was diagnosed with MND in January 2012, elected as a Trustee of the Association in autumn 2012 and have been a ‘campaigner’ locally and nationally since then.

During 2013 we achieved a lot in Oxfordshire, including:

• meetings with Oxfordshire MPs, Andrew Smith & Nicola Blackwood: both signed the MND Charter and both visited the MND Care Centre at the JR and learned about the work of the team and the research carried out in Oxford. They gave their support for a proposed dedicated respiratory physio’ service.
• persuading Oxford City Council and Oxford University Hospitals Trust to sign the MND Charter
• building links with the Personal Health Budgets (PHB) team to ensure that pwMND on NHS Continuing Healthcare are appropriately supported if they want to have a Personal Health Budget
• a number of interviews on Radio Oxford and BBC Oxford TV, raising local awareness of MND.

During 2014, it would be good to build on this, for example by getting more local organisations to sign the MND Charter – and/or by celebrating publicly those that have already done so.

It would be good to begin to see some fruit from these signings in terms of real change on the ground for people affected by MND.

One further thought…. over recent months I’ve had a growing feeling that we need a way of ensuring that the branch reflects, as well as possible, the views of those living locally with, and affected by, MND.

It would be very powerful to be able to say to a local politician / manager / policy maker: “We’ve consulted our local community of people living with MND on issue X & Y% agree strongly that…."

So…

• Would you like to be consulted more on local issues / questions for the MND community?
• If so, how might this work best for you? (email list, online forum, in person branch meetings etc. etc.)
• How do you think we can best ensure that MND Oxfordshire is seen to reflect the views of those of us affected by this devastating disease?

Do please email any thoughts to mark_stone@mac.com. We look forward to hearing from you.

Your stories needed for local campaign

Are you or do you know someone with MND who has been admitted to hospital with respiratory problems as an emergency in the last year?
Are you willing to tell us your story to help a local campaign?

If you think you might have an example, please contact Alice Fuller by email(alice.fuller@mndassociation.org) or phone (0207 250 8452). Alice is Campaigns & Development Manager at the Association, and leading this piece of work. All stories will be used anonymously unless express permission is given.

Join the MND Campaign Network

www.mndcampaigns.org
Fundraising and awareness

Having money in the Oxfordshire MNDA branch bank account means that we can always respond quickly to requests for contributions to help people in Oxfordshire living with MND and their carers too. We are also able to contribute to the costs of research and have enough to contribute to funds to help people living with MND in other parts of the country.

And each month money is raised and donated to us, most often by people living with MND and their families and friends, and through In Memory and Tribute Fund donations, because people want to keep that care and support going. Recently….

Bracelets for the Branch

These attractive expanding bracelets with silver MND letters, blue and orange beads and silver feet pendant were made by Vicky and her daughters Lily May aged 8 and Matilda aged 5.

They have been inspired by their Grandad’s illness to raise funds for the MNDA. The bracelets were very popular at our New Year event and will be on sale again at the AGM and Lunch.

Their Mum, Vicky is running, climbing and swimming with 6 friends in a tough ‘Hell Run’ on 26th April to raise funds for MND. If you would like to sponsor them or to know more details see: http://uk.virginmoneygiving.com/team/chrisjones

Jenny Rolfe will also be taking part in this gruelling event to raise money for MNDA. You can sponsor her at: www.justgiving.com/j9rolfe

Cuppa and carry

Hannah Venn, a member of Team Diddy, organised a raffle at a recent Baby Wearing coffee morning with all donations going towards our branch of the MNDA.

She managed to get an amazing amount of donations from different companies and was surprised by how many people had been affected by the disease. People were extremely generous and £310 was raised.

Central England Branch of the Nuclear Institute

This year, at the annual dinner of the Central England Branch of the Nuclear Institute, the MNDA Association, Oxfordshire branch was nominated to benefit from its donation to a charity.

The members collected a generous £1,191.00 during the evening. One of their colleagues had been diagnosed with the disease and having found out about the work of the Association they were keen to give their support as a tribute to him.
Oxford Orpheus raise voices and £9,000 for MND research projects at the John Radcliffe Hospital

The Oxford Orpheus choir, with help from the Oxford Branch of the MND Association and the generosity of an anonymous donor, organised this wonderful event in which singers came together to perform a rarely heard piece. It was a wonderful way to raise awareness of MND. Our research will also greatly benefit from the proceeds of the event. - Professor Kevin Talbot

A member of the choir tells us....

Oxford Orpheus was set up by Leo Pitt to continue the collaboration she began with Robert Dean eight years ago with a fund-raising ‘Come and Sing’ performance of Messiah. By now, Leo’s ‘brand’ and Robert’s charisma have built up a considerable loyalty among singers and players. Some even come from nether Sussex and darkest Dorset to take part. We join in because we love doing it, but it is also a great way to support a good cause.

This year’s workshop and concert was in aid of the Oxford University Motor-Neurone Disease research group. Professor Kevin Talbot sang in the bass section. He spoke of the heightened sense of awareness of the muscles needed for breathing and vocalization that singing produces, and of how appropriate it was for money raised by this event to be used to tackle MND. This idea, and the tragic nature of MND and Dvorak’s work, gave a unity to the occasion. The day ended with a stupendous performance- brass, timpani, massed strings and voices, topped by superb soloists, achieved a ravishing crescendo of sound, powerful enough to puncture the Town Hall’s ornate gravitas and turn performers and audience to emotional jelly.

Anne Silk’s view, whose inspiration and involvement was much appreciated...

The beautiful Stabat Mater text was written in the thirteenth century by a Franciscan Monk and set to music by Antonin Dvorak in 1877 after a time of illness in his own family. So it is appropriate that we were privileged to hear it here in Oxford Town Hall. All the expenses were met by an anonymous donor and all funds and collections were donated to the MND Care Centre at the John Radcliffe Hospital.

The Town Hall was full and many people with family and friends who had developed MND, as well as people with the condition itself, were in the audience. Professor Kevin Talbot gave a beautiful introduction to the work of the clinic and the research being carried out by his team. Such is the reputation of the MND Care Centre that patients are referred to it from many counties far beyond Oxfordshire itself – a great tribute to the care and treatment they receive.

Of course a choir cannot sing this magnificent work without the orchestra to accompany it. So we must thank the brilliant musicians who came from miles around to support and guide the singers in this concert. The whole event was designed to raise awareness of Motor Neurone Disease in Oxfordshire, where we have a statistically higher number of cases than expected.

And of course none of this could have come about without the planning, linking and cooperation of Leonora Pitt of the Oxford Orpheus. A special thank you to her for her brilliant organisation. We plan to repeat this successful fund raising concert in 2015 and look forward to working with Robert Dean and Leonora in the future.

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

Look carefully at this picture and you may see our very own Rocky Horror, Mark Stone.

Friends of Mark threw a Rocky Horror Show – themed party and at the end had a whip round and made a donation of just over £100 to our funds. Thanks!

Please let us know about your fundraising or awareness campaign and we will include your story or event in the next newsletter. Information and photographs supplied to the branch secretary Lesley Ogden at lao.ogden@googlemail.com

How the money raised has helped

We have...

- Contributed to the cost of counselling for people living with MND and for carers too
- Covered the cost of a professional development day for a paid carer working with someone living with MND
- Paid for taxis to hospital and other appointments and to branch Friends and Family and other events
- Covered the costs of complementary therapies
- Given books about MND to the Oxford Care Centre to give to every newly diagnosed person
- Helped with heating costs
- Made donations to help with the costs of relocation
- Contributed to the costs of a powered wheelchair and a riser recliner chair
- Helped with the costs of supervised gym sessions
- Contributed to the MNDA Chief Executive’s annual appeal and given money for care and support, research and campaigning across the country
- Made our annual end of year transfer of funds to the national office to support all aspects of the work of the MNDA

Oxfordshire MNDA Branch signs the MND Charter

The Branch, like many individual members, has signed the Charter in recognition of the rights and priorities of people living with MND and of their carers.

The five point Charter sets out what good care looks like for people with MND and their carers. It is designed to raise awareness of and understanding of this devastating disease so that people living with MND get the care and support they need in the right place and at the right time.

If you would like more information about the Charter and to sign up please visit www.mndassociation.org/mndcharter

Sign the MND Charter
Search for MNDA Charter

MND Connect is available 9am to 5pm and 7pm to 10.30pm Mondays to Fridays. Calls charged at local rate.

08457 626 262
Oxford Sailability
Would you like to try wheelchair-accessible sailing this summer?

Would you like to try wheelchair-accessible sailing this summer? Even if you consider yourself a non-sporty land-lubber, you might be pleasantly surprised to discover an amazing freedom of movement on the water while enjoying exploitation of wind power (in a specially designed dinghy, yacht or tall-ship).

(1) Oxford Sailability, based at Farmoor Reservoir, is a group of friends from in and around Oxfordshire who meet on Tuesday evenings (April to October, weather permitting). Newcomers are welcome to have a go (no charge, then £3 per sail or £25 p/a). The dinghies (1 and 2-seaters, including Challenger trimarans, Access dinghies and a paralympic-class Skud) are safe, stable, easy to control and accessed via the new wheelchair-friendly pontoon. MNDA members and friends would be very welcome at the Oxford Sailability ‘Start of the Season’ supper at Farmoor on Friday 28th March.

In addition, thanks to generous contributions from Solent-based charities to the MNDA raffle held in October, the winners – members of Oxford Sailability – would like to share their prizes and introduce MNDA members to the following unique opportunities:

(2) A one-day sail from Southampton on Saturday May 10th on the Jubilee Sailing Trust’s tall ship Tenacious (2 places left for a pwMND and friend/helper. URGENT – If you are interested in this Tenacious event please Email jhouchin@wiley.com ASAP!
(3) A day sail from Portsmouth in Mike Wood’s Disabled Sailing Trust’s catamaran yacht (up to 8 people including wheelchairs – date to be arranged).
(4) A day trip in Geoff Holt’s wheelchair-accessible speedboat Wet Wheels on the Solent (up to 3 wheelchairs - date to be arranged).

For more information about any of the above events, including the Oxford Sailability supper on 28th March, please email Jane Houchin (jhouchin@wiley.com). See jst.org.uk, disabledsailing.org, and wetwheels.co.uk for photos and videos from the Solent.

A relaxing evening of music & humour - Saturday 10th May 7.30pm

St John the Baptist Church, Main Street, Grove, OX12 7LQ

“Maytime Music”

Eclectic mix of light classical, humorous and songs from shows and featuring the group Sound Foundation
Tickets (£8; £5 concessions) Obtainable from Cornerstone Coffee Shop, Grove, OX12 0PT, or at the door
Light refreshments will be provided

Proceeds divided between Oxfordshire MND Association and Church Funds

We never lose hope. We strive to find a cure for MND, and to support everyone affected by this devastating disease
The MND Association National AGM and conference will be held on September 12th and 13th this year, see the website www.mndassociation.org or Thumb Print magazine for details. It is always a friendly and informative event where people from the MND community meet together with others from all over England, Wales and Ireland. Moira McIver writes about her visit in 2013:

This was the third time that I have attended the MNDA AGM, at the Radison Blu at Stansted and it was the most enjoyable. The first thing that strikes one about the Radison is how clean it is and how it seems devoid of staff! Even the drop off area looked as if it had been laid with new stones - so clean and shiny in the sun.

I wheeled through to the MND desk and went into the main conference room but was soon out again for coffee then I went into a small workshop on Future Planning of the MNDA. I joined a small group discussing Care issues. I found myself sitting next to the Chief Exec, Sally, whereupon I made sure that I got my points across!

Next was a lovely buffet lunch of cold curried chicken and red grapefruit. I met up with old friends. Then they announced that the conference was resuming. Before I went to the conference room I thought I’d see if there were any staff in the restaurant clearing tables. Alas, the room was completely cleared and emptied!

After lunch, Prof Kevin Talbot gave a very interesting talk on the latest research. I’m not going to go into detail on this just in case I’ve got the facts wrong! We wound our way home after a most enjoyable AGM.

Book now for 2014 Spring Conferences!

These regional events will focus on current news in care, research and campaigning and feature display stands where information can be accessed. They are aimed at people living with MND, who can attend for free, their carers and families as well as volunteers.

View the programme and register now at: www.mndassociation.org/news-and-events/events/conferences/spring-conferences or phone 01604 611837. The Branch is able to offer transport costs to all these events if needed.

Branch contacts

Members of the committee may be contacted through the Branch Secretary.

<table>
<thead>
<tr>
<th>Name</th>
<th>Email</th>
<th>Telephone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chairman</td>
<td>Lynda Wigley</td>
<td></td>
</tr>
<tr>
<td>Treasurer</td>
<td>Mike Beaumont</td>
<td></td>
</tr>
<tr>
<td>Secretary / Family &amp; Friends Group</td>
<td>Lesley Ogden</td>
<td>01235 850372</td>
</tr>
<tr>
<td></td>
<td>Marilyn Hamblin</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Anne Silk</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Tim Kennedy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Rebekah Sammut</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Jane Street</td>
<td></td>
</tr>
<tr>
<td>Digital Media Officer &amp; Newsletter</td>
<td>Matt Jones</td>
<td></td>
</tr>
</tbody>
</table>

MND Connect is available 9am to 5pm and 7pm to 10.30pm Mondays to Fridays. Calls charged at local rate. 08457 626 262