

Summer
2017

Welcome to the Notts Branch Bulletin. We hope you enjoy reading about the latest fund raising efforts by branch members and supporters and don't forget if you are organising an event and would like to publicise it in the next Bulletin please contact the Branch Chairman or Secretary.

Some amazing fundraising

Jon Hickinbotham (*the Treasurer's son-in-law!*) has raised over £1,300 for us by running his first London Marathon in April.

Many congratulations and thank you so much for supporting us – all the hard work was worth it!



Jo Cordon and Lynsey Wortley presenting a cheque for £3,254 to our Treasurer, Roger Spells, at May's "Second Thursday" meeting. The money was raised by Portland College staff, students and friends at a recent evening in support of Lynsey's father, Dave Wortley. Thank you all!

Leanne Fotheringham recently completed a Skydive to raise money for the MNDA Nottinghamshire Branch. Leanne's Grandad was diagnosed with MND back in 2006 and continues to suffer with the disease, which prompted Leanne to help raise much needed funds. When she landed, she wanted to go back up and do it all again, and she now plans to do a wing walk next, all for MND...Leanne has so far raised over £800! Amazing work Leanne! justgiving.com/LeannePFotheringham



The North Notts Support Meeting

Last month we had a very interesting demonstration of communication aids & the different controls which can be used with them.

Simon Judge from Barnsley hospital gives a very specialised service over a large area. He also spoke about voice banking & blending.

Walk to D'feet

Please come along and support us to raise money and awareness of MND on Sunday the 3rd of September at the Sherwood Forest Country Park, NG21 9HN.

We shall be taking a leisurely stroll through this beautiful forest where the 'Major Oak' can be found as well as many other trees and wildlife. The walking trails are well suited for wheelchair users or electric scooters and we expect to see families joining us. Dogs are also welcome in the park provided they are on a lead.

For those that want to stretch out there is a 2 mile route, but for those less able we have a shorter route of just over 1 mile.

For registration forms and sponsor forms please contact walk leader Barry Wilson by email at barry@mnd-notts.org.uk

Radicava or Edavarone

Some of you may have read about the drug Radicava also known as Edavarone. The FDA have now approved it's use in America. It is already in use in Japan and Korea.

The top line is that it has shown to slow down the disease progression when administered in the early stages of MND. The drug is administered intravenously (directly into a vein) every 2 weeks and the annual cost is about one hundred thousand pounds. Whilst the MND-ALS community is very excited about this new development, we should not get too enthusiastic as we need to see a realistic option before the UK health authorities will support it. A pharmaceutical company in Holland is working on a tablet version.

For more information you can contact the MNDA research team research@mndassociation.org or 01604 611880



Take part in Silence Speaks to raise vital funds for MND Association – you can do a few hours, a day or even more!

Sign up as an individual, team, school or workplace and raise funds and awareness for our branch or in October this year!

To find out more visit www.mndassociation.org/silencespeaks to register for your pack or contact us at fundraising@mndassociation.org



If you do not wish to receive any further correspondence from the local branch of the MNDA, please let a member of the committee know. We never lose hope. We strive to find a cure for MND and to support everyone affected by this devastating disease.

Motor Neurone Disease Association - Registered Charity No: 294354

Record “Second Thursday” attendance at May meeting

The “Second Thursday” format must be pleasing most of the people most of the time as numbers attending continue to average 40 each session and in May we had 50, which was the best ever!

Sadly and inevitably, we do sometimes lose much loved friends, some of whom were with us from the first meeting over five years ago. We do however enjoy a higher profile these days, in no small part due to recommendations by the health care professionals at the MND Care Centre at the QMC. Add to this our interactive website with our much praised video and it’s no surprise that we continue to welcome new people on a regular basis.

In March, Sharon King, the MND Regional Fundraiser for the East Midlands spoke to the group about the numerous fundraising activities planned in Nottinghamshire this year, whilst in April we held one of Godfrey’s famous quizzes! At our May meeting, Mike Newbold was our speaker. Mike, a local man, retired early from a business career and now has a new acting career as a “Supporting Artist” (or “Extra”) appearing in numerous well known TV and film productions. He gave a lively presentation of life behind the scenes which was very well received by those present. At our next meeting on June 8th we have Elaine Leatherland talking about the complementary therapies that she offers to people with MND, and on July 13th, we have Cllr Viv McCrossen, the newly appointed Mayor of Gedling, who has chosen MND as her Charity of the Year.

Finally, at the time of publication we still have a few places left for our annual riverboat trip cruising the Trent. We set sail at midday on Thursday August 3rd and we disembark at 2.30 pm after a hot three course lunch on board. All people living with MND and their carers are welcome, although places are very limited. Enquiries to Roger at roger@mnd-notts.org.uk

Roger standing for MNDA Trustee

We would like to wish our very own Roger Spells all the very best in his attempt to become a trustee of the MNDA in the forthcoming elections. Members of the MNDA will have a chance to vote for Roger in the next few weeks

Dates for your diary – See website calendar for more details

8 th June	‘Second Thursday’	The Mapperley Plains Social Club at 2:15pm
21 st June	North Notts Support Group	Retford Library, DN22 6PE 2 – 4pm
25 th June	Tea4MND Garden Party	The Walled Garden, Beeston Fields Golf Club at 2-8pm, Tickets: £40, Contact: Pete Collins on 07896 532342 or Tea4MND@hotmail.com
25 th June	3k & 5k Community Fun Run – Ilkeston, Derby	Raising funds for the Nottingham Branch Contact: Run@st-johnhoughton.derbyshire.sch.uk
27 th June 6 th July	Grand Prix 2017	Holme Pierrepont Running Club @ 7:15pm www.hprcrun.co.uk/gp
28 th June	Eric Gibson Golf Day	Beeston Fields Golf Club, NG9 3DA
13 th July	‘Second Thursday’	The Mapperley Plains Social Club at 2:15pm
19 th July	North Notts Support Group	Retford Library, DN22 6PE 2 – 4pm
3 rd Aug	River Boat Trip	Colwick Park Marina, Midday
10 th Aug	‘Second Thursday’	The Mapperley Plains Social Club at 2:15pm
16 th Aug	North Notts Support Group	Retford Library, DN22 6PE 2 – 4pm
2 nd Sept	The MND Masquerade Ball	The Crowne Plaza, Nottingham. Tickets: £49 Contact: mndfundraise@gmail.com
3 rd Sept	Walk to D’feet	Sherwood Forest Country Park, NG21 9HN Contact: barry@mnd-notts.org.uk

Treasurer’s Report

It has been an excellent three months since the last Bulletin, as we had had new income totalling over **£10,000** coming into the Branch. This included donations of a total of **£3,390** from Portland College in support of Dave Wortley, **£2,465** raised by Charlie Day and friends in memory of his father, **£1,150** from Wysall & Thorpe Villages, the first **£790** from Jon Hickinbotham’s London Marathon sponsorship, **£310** from David Williamson and **£232** from Ruth Thirtle. Thank you all so much - your efforts are really appreciated and make a big difference to our ability to help local people with MND, as well as enabling us to make a significant contribution towards research into this terrible disease. We have also banked the **£1,700** profit from our Race Night in February and received **£2,472** in ‘in memoriam’ donations.

I am pleased to say, as well, that we have been able to make grants totalling over **£6,500** for a range of support needs, including house adaptations, hoists, stairlifts and carers grants. If anybody living with MND has a requirement for any sort of financial support from the Branch, then could they please contact me or our MND Regional Care Development Advisor, Kim Iliffe (kim.iliffe@mndassociation.org). We are always open to any reasonable request for support.

The 59 Club was won by Alan Whitely in February, Gerry Thompson in March and our Chairman, Mike Cole, in April Congratulations to you all! There are still a few spare numbers available – if anyone would like to support the 59 Club by donating £4 a month, please contact me.

Roger Spells (Treasurer)

Branch Contacts

Branch Chair	Mike Cole	Tel: 07775 613 114	e-mail: mike@mnd-notts.org.uk
Branch Vice Chair	Simon Fotheringham		e-mail: simon@mnd-notts.org.uk
Branch Secretary	Nina Squires		e-mail: nina@mnd-notts.org.uk
Branch Treasurer	Roger Spells	Tel: 0115 923 2709	e-mail: roger@mnd-notts.org.uk
Branch Contact	Gerry Thomson	Tel: 07505 023 117	e-mail: gerry@mnd-notts.org.uk
Second Thursday Coordinator	Godfrey Kent	Tel: 0115 937 3318	e-mail: godfrey@mnd-notts.org.uk
Branch Webmaster	Jonathan Pykett	jp@mnd-notts.org.uk	www.mnd-notts.org.uk

MND Association Contacts

National Office	Tel: 01604 250505	e-mail: enquiries@mndassociation.org
MND Connect	Tel: 08457 626262	e-mail: mndconnect@mndassociation.org
MND Association National Website		www.mndassociation.org