

Spring
2019

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.

Second Thursday continues to Buzz!

Anyone who has been to a Second Thursday meeting recently will be aware of a real buzz around the place as more and more people hear about the friendship and support that is readily available to everyone who walks through the door of the Mapperley Sports and Social club where we gather once a month.

In December we all went festive and had a good time at our annual Christmas party. As usual everyone brought something to eat and to share with fellow members. Godfrey's legendary Christmas quiz wasn't quite as smooth as usual. Primarily because he seemed to want to check the scores before he had read out the answers. This caused much merriment in the ranks. However, he battled on like "a good 'un" and after much confusion a winning team emerged from the chaos.

In January, normally a quiet month, we were graced by over fifty people including a record twenty one who were living with MND. This created a good atmosphere for our guest speaker, Erica Littlewood, the MND Care Coordinator at QMC. She skilfully led us through the delicate and emotional subject of Advance Care Planning and fielded a host of questions at the conclusion of her presentation.

In February, we didn't have a speaker and instead had our own version of "speed dating" where we encouraged people to move around and talk with someone they don't normally talk to. It worked well and as usual, we had trouble getting everyone to leave the building on time!

Fundraising

As the new financial year begins again and people are busy thinking about how they can raise funds for our Branch, I just wanted to make sure you are all absolutely clear what needs to be done when setting up online fundraising pages.

Basically if someone is looking to raise funds for our Branch, they MUST state this clearly on any online fundraising pages they set up such as Just Giving / Virgin Money Giving etc. The MNDA need an audit trail and to show transparency when fundraising so the public are absolutely clear how their donation is being used. If this is not done, your funds will automatically be allocated to general funds for the MNDA.

An example of this would just be a simple one liner at the top of the page stating something along the lines of 'All funds will be donated to the Nottinghamshire Branch of the MND Association and will be used locally to support people living with MND in the Nottinghamshire area'.

This also applies to anyone fundraising on your behalf who produces printed materials/online promotion of their event/activity. Just a simple one liner somewhere that clearly states they're raising funds for the Nottinghamshire Branch is all that's needed.

If you become aware of any fundraising activity then it would also be useful to inform the MNDA so they can make sure the page is linked to our Branch and everything is coded correctly so funds are then automatically transferred.

Dates for your diary – See website calendar for more details

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|----------------------|---------------------------|---|
| 14 th Mar | 'Second Thursday' | The Mapperley Plains Social Club - 2:15pm |
| 20 th Mar | North Notts Support Group | The Well, DN22 7BD - 2 – 4pm |
| 21 st Mar | Branch AGM | The Beeches Hotel, Wilford Lane, NG2 7RN 7:15pm for 7:30pm start - Guest: Jan Warren |
| 30 th Mar | Race Night | The Sir Julien Cahn Pavilion, West Park, Loughborough Road, West Bridgford, NG2 7JE At 6:30pm |
| 11 th Apr | 'Second Thursday' | The Mapperley Plains Social Club - 2:15pm |
| 17 th Apr | North Notts Support Group | Retford Library, DN22 6PE - 2 – 4pm |
| 9 th May | 'Second Thursday' | The Mapperley Plains Social Club - 2:15pm |
| 15 th May | North Notts Support Group | Retford Library, DN22 6PE - 2 – 4pm |
| 13 th Jun | 'Second Thursday' | The Mapperley Plains Social Club - 2:15pm |
| 19 th Jun | North Notts Support Group | The Well, DN22 7BD - 2 – 4pm |

SCRAP 6 MONTHS As some of you may be aware, the MNDA are campaigning for criteria of the SRTI fast-track process for claiming benefits to be amended. Currently the SRTI requires a 'reasonable expectation of death within six months', which excludes many people with an unpredictable terminal illness like MND. We would like to see the Government change the law, as Scotland has recently done, to move away from the 6 months definition towards a decision made by a clinician.

To learn more or sign the petition, please search for 'scrap-six-months' on the MNDA website.

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.



Branch AGM

Just a reminder that our branch AGM is this month on Thursday 21st March 2019 at 7.15pm (for 7.30 start). It will take place at The Beeches Hotel, Wilford Lane, West Bridgford, Nottingham NG2 7RN.

We are delighted to welcome Jan Warren, Vice Chair of Trustees for the MND Association as our speaker. She will be coming to talk to us about her experience with MND, why she supports us and her role as a Trustee. We are sure it will be a very informative and enjoyable evening and we look forward to seeing you there and also enjoying the ample buffet that's put on.

MND Register

The MND Register is a national project funded by the MNDA who's aims are to collect data on people with MND living in England, Wales and Northern Ireland.

There is currently no nationwide register that records clinical information about people with MND, and the estimate of how many people have MND remains unknown. The data we collect can help us to learn how a person is affected by MND, how the condition progresses and how many people have MND in different areas of the UK.

Anyone with a diagnosis of MND living in England, Wales and Northern Ireland can participate in the project. Registries like this help specialists gain knowledge about MND and this information is vital for planning appropriate medical care and treatment. Eligible participants can take part by visiting our website <https://mndregister.ac.uk/signup> and self-register

Obituary

PHIL WATHALL 17th April 1964 - 25th January 2019

Phil Wathall was a big man in every sense of the word. No one who met him could ever forget his genial persona combined with a wicked sense of humour. Phil was diagnosed in 2011 and despite living with MND for eight years, latterly harnessed to a "Nippy" breathing machine, not an ounce of self pity was evident.

Phil and his devoted partner Helen, never let MND get in the way of anything they wanted to do. That is why they were ever present at the "Second Thursday" meetings and rarely missed a social event such as the river cruise or quiz nights. Phil was a total inspiration to everyone, accepting his fate with a quiet dignity that the rest of us could only watch in admiration

His funeral took place on Wednesday 27th February at the Amber Valley Crematorium. Unsurprisingly there was standing room only as moving tributes were paid to Phil initially from Rosie, his daughter then from Helen. Over a dozen members of "Second Thursday" were present to give him the send-off he richly deserved,. After the service, Helen had kindly organised refreshments at the Bell Inn at Smalley where people met old friends and some new ones, all sharing their memories of Phil in the picturesque Derbyshire surroundings



Treasurer's Report

Our financial year ended on December 31st and it was a near record year with total income of over £56,500. This was achieved by the efforts of a large number of generous and supportive fundraisers, but particular mention should go to the Eric Gibson Golf Day, which made a colossal £16,500, and Viv McCrossen, last year's Mayor of Gedling, who nominated MNDA as her Charity of the Year, and donated £9,130 to the branch, as well as a similar amount to National Office. I'd like to pass on my sincere thanks to all of the people who gave their time and money to support us.

As for our expenditure last year, we spent over £32,000 on patient care, making a total of 59 grants to 33 different people living with MND. I will give further information on last years accounts at the AGM on March 21st.

The new financial year has also started off well with donations of £1,500 in the six weeks so far, including £1,000 from Christine Morrall who got sponsorship for a "dry November". The only grant made so far is a Young Persons grant of £250. 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 Barry Lenton in November, Gerry Thompson in December and Laura Hickinbotham in January. Congratulations to you all.

Roger Spells (Treasurer)

Branch Contacts

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| Association Visitor | Denis Shields | Tel: 0115 982 0029 | e-mail: denis@mnd-notts.org.uk |
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MND Association Contacts

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