

Support Meetings

We hold support meetings in Swindon and Calne.

Swindon meetings are held at The Lawns Community Centre Guildford Road, Swindon, from 2.15-4pm. The next ones will be 27th November, 15th January and 19th March. Contact Susanne Webb on **07776 126994** or email susanne.webb@gmail.com

Calne meetings are held at The Masonic Hall, Stainer Road, Calne, from 2.15-4pm. The next meetings will be 18th December and 19th February. Contact Moya Wallis on **01380 859611** or email moyawallis@hotmail.com

All sessions are drop in. Come along to share ideas, meet other members and for a change of view! Volunteer helpers also welcome.

Chair's welcome

We were all delighted that for a few weeks this summer, the Ice Bucket Challenge placed Motor Neurone Disease in the public eye. As well as having lots of fun, many people became aware of the challenges this disease causes for the first time and it raised a staggering £7 million whilst increasing overall awareness.

The executive and trustees of the Association are now considering how to spend the money and all members have the opportunity to add their views. Many of our friends were involved and we send our grateful thanks to all those who took part.

Enjoy reading this issue and please do let us have your views and stories.

Alison Aviss

Don't let me die without a voice

Losing your voice and the ability to express your feelings and wishes to loved ones in the last weeks or months of a person's life must be a terribly frustrating and frightening experience. Sadly, this is the reality for some people living with MND. The MNDA recently launched a new campaign '*Don't let me die without a voice*'. They're asking supporters to email their candidates standing in the next general election to commit to ensuring that people living with MND get the communication support they need.

You can help to change the situation. Over 1,000 people have joined the campaign already. This is fantastic, but the more

people who contact their candidates, the more likely they will commit to working with the MNDA on this important issue.

If you have experience of trying to access communication support, the All-Party Parliamentary Group (APPG) on MND wants to hear from you. These parliamentarians are so concerned about this issue that they have launched a formal inquiry. Please take their short survey at <https://www1.pickersurveys.org/snapwebhost/s.asp?k=141078032694> and show the Government the true reality of this issue. Your contribution counts.

Great North Runner

Following last year's success in completing the Loch Ness marathon, Heather, our Vice Chair and Campaigns Co-ordinator, has this year taken on the shorter challenge of the Great North Run. The iconic half marathon was run on a warm September day and over 300 people ran in support of the MNDA.

The event also celebrated its one millionth finisher this year.

'The sun was pretty relentless for the first half of the run', Heather said. 'I was really pleased to see the sea at South Shields. Even though there was still another mile to go at that point, at least there was a sea breeze, albeit gentle!' Heather has already taken the ice bucket challenge but perhaps she should have saved it for after the run to cool down!



Cream teas in Tockenham

On Sunday 17th August Pam and Anna Gough hosted a cream tea in their village of Tockenham. As the weather looked a bit uncertain, the event was held in Tockenham village hall, which was just as well given the number of people that turned up.

It was a super day – as were the cakes – and an amazing £563.33 was raised. Money is still rolling in, and the total now stands at £646.49. That's a lot of cake!"

Curry Evening

If running isn't for you, there is always eating for charity! On 8th October 27 people attended a curry evening at the Bombay Lounge in Peatmoor. Generously, the restaurant donated a percentage for each meal bought.

It was a great evening of conversation and food. Various supporters gave prizes which were raffled: Dawn Connolly (theatre tickets) in memory of her mum; Julie Lewis Smith of Wilson's Hair Studios (cut & blow dry); Ewa Douglas of Hypnoewa.com (Reiki massage session); and a glorious cake (fit for the Great British Bake-Off) by Liz Jenkins of Little Mouse Cupcakes.



John Lewis donation

The North Wilts Group was fortunate to be invited to take part in the John Lewis Community Matters scheme, in which customers 'vote' for a local charity by putting their charity tokens in a plastic box. The photograph shows Barbara and Susanne being presented with a cheque for £842. Many thanks to John Lewis.



Local support for local people

A National Perspective

Heather Smith

MND Association AGM

Heather attended the AGM on 13th September. As expected, there was a lot of talk about Ice Buckets! A presentation was made to Paula and Robert Maguire, who brought the idea over to the UK. Sally Light's report praised their work and all the support the challenge had had, and Anne Bulford, the Treasurer from the Trustees, was able to add that, even without the Ice Bucket challenge, income for this financial year was at record levels.

It was lovely to see the work of the North Wilts Group represented in the exhibition stands and the workshops. The Volunteering stand had a slideshow featuring images of the cake sale at Nationwide and the presentation of the cheque following the Jovial Monk golf day. The Campaign stand had a focus on recruiting more campaign contacts, featuring images of the current contacts, including Heather. The Campaign workshop also featured a recruitment video with contacts talking about why they campaign, their relationship to MND, the importance of campaigning, and how easy it is to get involved. A great opportunity for Heather to talk about the excellent work in North Wilts!

The afternoon session featured a powerful speech from the incoming Chair of Trustees, Alun Owen, about his personal experiences of MND. There was also a fascinating presentation from Professor Ammar Al-Chalabi about the influence of nature, nurture, age and chance in the development of MND. Startling to note that MND is now the most common neurological disease in midlife with three people diagnosed everyday. Both speeches, and more, are available on the live stream – worth a watch!: <http://new.livestream.com/eventstreamingcompany/>

Disability Pride, Belfast

Heather attended 'Disability Pride, Belfast' on 21st September. 'Disability Pride' began in Chicago 11 years ago. It is a parade through the city aimed at celebrating the ability of disabled people. Each year a new city is asked to join the event. Belfast is the first city outside the USA and Canada to be asked to take part.

The event was brought to Belfast through the efforts of Michael Holden who is living with MND. Michael, supported by a team of colleagues, has worked hard throughout the year to organise a parade of over 20 disability organisations through Belfast to the City Hall, where followed a carnival of music, dancing, food, and the opportunity to visit various trade stands. The event went on all day and was attended by thousands of people.

Heather said, 'I went along to Disability Pride to represent my employer, the National Trust, but it was great to be able to wear my 'MND' hat as well and support Michael and his colleagues from the MNDA NI branch. There was lots of awareness of MND raised. It was a fantastic event with drama and music groups involving disabled people taking the stage to entertain the crowds! Roll on next year's event ...'

Useful Contacts

N Wilts Group website
www.mndnorthwiltshire.org.uk

N Wilts Group contact
info@mndnorthwiltshire.org.uk
or phone MND Connect

Facebook <http://www.facebook.com/MNDNorthWiltshire>

Twitter @MNDNorthWilts

Letters will be forwarded from:
North Wiltshire Group, c/o MNDA,
PO Box 246, Northampton NN1 2PR

MNDConnect 08457 626262

MNDA national website
www.mndassociation.org

MNDA Volunteering Team
01604 611681

Hilary Fairfield, MNDA Regional Care
Development Advisor 08453 751828 or
hilary.fairfield@mndassociation.org

Prospect Hospice 01793 813355

Dorothy House 01225 722988

Paul Wilkinson

We are saddened to report that Paul Wilkinson died on 5th September. He was an effervescent and highly active member of the North Wilts Group – made more remarkable as Paul was diagnosed with MND 10 years ago! Among other things, Paul conquered Swindon's steepest hills and completed a backward marathon at the County Ground – all from his wheelchair.

In total he collected over £30,000 for the MNDA and Prospect Hospice, and was honoured with a Pride of Swindon Award. He will be missed. Our condolences are extended to his family.

Support for You

What's On?

6th November

Committee Meeting, Prospect Hospice, 7pm

27th November

Swindon Support Meeting, The Lawns

4th December

Committee Meeting, Prospect Hospice, 7pm

18th December

Calne Support Meeting, Stainer Road

15th January

Swindon Support Meeting, The Lawns

5th February

Committee Meeting, Prospect Hospice, 7pm

19th February

Calne Support Meeting, Stainer Road

5th March

Committee Meeting, Prospect Hospice, 7pm

Knitters urgently required

Are you a knitter? Do you have a bit of time and some scraps of wool? If so, your skills are urgently needed. At Easter it was chicks; now its Christmas tree stockings!

Tesco Extra on Ocotal Way and Sainsbury Stratton have both donated chocolate bars to fill the stockings to make attractive seasonal gifts.

For details and a pattern, email info@mndnorthwiltshire.org.uk

This is YOUR Newsletter. If you have any comments, suggestions or news items please do contact me on AndrewRSargent@gmail.com

The deadline for submission for the next issue will be **16th January 2015**.

Andrew Sargent

Registered Charity No 294354



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