

Note from the Chair

There's a distinct wintery feel about this newsletter with the Bath Christmas Market on the horizon again - don't forget that we need donations of prizes for the Tombola again that was such a great success last year.



But let's not get ahead of ourselves, there is still (hopefully) a beautiful autumn to enjoy. With this in mind we arranged an afternoon trip out for carers at the end of October on a steam train from Bitton with a cream tea thrown in. This is just one example of how we are using the lottery funding to support the support groups.

Talking about support, one issue that is high on our agenda is the need to recruit more Association Visitors (AVs) to support people with MND. Please read the article and think about how you might help identify suitable candidates for this crucial role.

Andrew Grundy

The Bristol & Weston group are holding a Christmas party on Saturday 14 December (2pm) at Eden Grove Methodist Church, Bristol, BS7 OPQ 2.00pm.

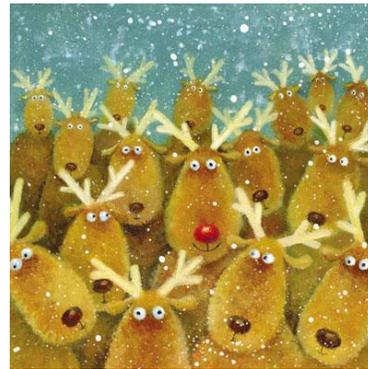
*****ALL VERY WELCOME*****

Join us for carol singing and mince pies – there's even a rumour of a visit from Father Christmas! We look forward to seeing you all there!

The countdown to Christmas is on!

Like it or loathe it Christmas is just around the corner and we are embracing the imminent festive season by planning our return to the bustling **Bath Christmas**

Market on Tuesday 10 December. We will have a stall there from 10am – 7pm and will be selling festive goods as well as running a tombola which was a great success last year (all donations very welcome!). If you are local, do come and say hello, we would love to see you. We are looking forward to raising both funds and awareness of MND and of our local group. If you have time to come and help us on the day, we would welcome any volunteers. Please contact Agnes for further details.



Meanwhile, you can purchase your Christmas cards and other merchandise at the MND online shop which is now open at:

<http://www.mndassociation.org/news-and-events/Features/Christmas+Shopping>

Also at this link you can find out how to make money for the Association when you shop at your favourite high street stores. Happy Christmas shopping one and all!

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Line dancing for MND

Two friends – Pam and Monica – organized an evening of line dancing at Eden Grove



Community Hall, Bristol on Friday 20 September.

They decided to hold a fundraising event after attending the Bristol Support

Group meeting. They were moved by how welcome they were made to feel and decided to raise funds and awareness for the group. Pam, who is living with MND, took to the floor with Monica and they performed several line dances.

The evening was a massive hit and an impressive **£526** was raised for the group! A cheque was presented to Ray Hulbert by Pam and Monica (pictured) at St Peter's Hospice on Saturday 28 September at the monthly support meeting.

We are grateful to Eden Grove Community Centre who very generously provided the venue free of charge and to Sainsbury's who also supported the event by providing raffle prizes.

Knitting a giant motor neurone at Bristol Harbourside

On Sunday 1 September 2013 two creative Bristol ladies spent the day at Bristol Harbourside knitting a giant motor neurone to raise awareness of MND. Their aim is to use their trusty needles to create a scaled-up motor neurone



1,000m long! They said the day was a great success and they spoke to lots of people interested in the project and about motor neurone disease and the work of the MNDa. They hope to repeat the day and extend their growing neurone again soon – watch this space for updates.

We need your help!

A group of people interested in a range of neurological conditions has been meeting regularly in Bristol with the aim of improving neurological services in the Bristol, South Gloucestershire and North Somerset area. This group has named itself the **Brunel Neurological Alliance**. It represents people with all neurological conditions, not just MND (e.g. multiple sclerosis, Parkinson's, stroke, epilepsy). Would you like to make a difference by joining this group and helping us to change services?

The Alliance is trying to get as much information as possible about the experience of people with neurological conditions in the area, and to this end, has developed an online survey. It would be really helpful if you could take the time to fill this in. The survey is quite long (about 80 questions!) but your input is extremely valuable – the results will be collated into a report which will be discussed with local health and social care managers and will help to influence how services are provided in the future.

The survey can be found at: www.surveymonkey.com/s/NeurologyExperienceBristol

For further information about Brunel Neurological Alliance or the survey, please contact your Regional Care Development Adviser, Hilary Fairfield, on 0845 375 1828 or hilary.fairfield@mndassociation.org

I Am Breathing film – screening from Bristol to Westminster!

'I Am Breathing', a moving film about a young father with MND who wanted to leave a lasting memory for his son, has been shown in cinemas around the UK and worldwide. Its launch in June received acclaim in the national media and it is a useful tool for raising awareness about MND.



In October, Hilary Fairfield (MNDa Regional Care Development Advisor) hosted a viewing of the film for twenty-eight local

health and social care professionals in Bristol. Like most audiences they were moved by the film and gave the following comments:

'Very thought-provoking'

'Insight from a person with MND – really makes you think and reflect'

'As professionals we have such a minimal insight into the reality for these patients'

The MND Association has a key role in raising awareness of this condition and we appreciate anything our local members can do to help us in this aim.

Also in October, the award-winning film was screened at the House of Lords to raise awareness among politicians. Many more MPs and Peers signed the MND Charter at



the screening which was followed by a talk from Neil's widow Louise.

The event was co-hosted by Baroness Royall and Gavin Williamson MP, the chair of our All-Party Parliamentary Group on MND (pictured).

To donate funds to your local group:
Text **'BBWW73 £5'** to **70070**
or visit our Just Giving page at:
www.justgiving.com/MND-BBWW

100k walk for MND

Congratulations to Laura Williamson who completed a 100k walk for MND in September in less than 24 hours! This most recent walk, her second in six months, was from Putney to Henley along the Thames pathway.



Laura had great support from family and friends and raised £700 bringing her total raised this year to over £1,300. Well done Laura!

Could you support someone with MND and become a visitor?

As you are probably aware, a diagnosis of motor neurone disease can be a frightening and isolating experience. Sometimes all that people need is a friendly face and a listening ear to make a real difference to their lives.

Our group really needs people like you to help make that difference. We are currently seeking people to volunteer as Association Visitors (AVs) in **south/east Bristol and Weston-super-Mare.**



Association visitors play a vital, valued and unique role in helping us to ensure people with MND and their families receive the support and services they require. Becoming a visitor can be a rewarding, enriching experience. Those who

train as visitors come from all walks of life, and all backgrounds. You don't need personal experience of MND - just the desire to make a difference.

As an AV you will work as part of a close-knit local team, offering a vital link between people with MND, their local group or branch and other sources of support. In return for your time, you'll make some wonderful new friends and receive free training, which has won national recognition!

For more information on how you can become an AV and the application process, please visit www.mndassociation.org/get-involved/volunteering or telephone 0845 6044150.

Support Group Days

There are two support groups that people living with MND and their carers can attend each month in the Bristol, Bath, Weston & Winsley area.

Bath and Winsley area

1st Friday of the month at
Winsley Church Hall, BA15 2LH
1.30-3.30pm

6 December 2013

3 January 2014

Contact: Daphne Cox
01225 868224
daphne@daffers.org.uk

Bristol and Weston area

Last Saturday of the month at St Peter's
Hospice, Brentry, Bristol, BS10 6NL
2-4pm

30 November 2013: Talk from Patrick O'Neill – specialist in wills and powers of attorney

14 December @ 2pm: Christmas party at Eden Grove Methodist Church, Bristol, BS7 0PQ. All very welcome!

2014

25 January

22 February

29 March

Contact: Ray Hulbert
0117 9755492
ray@mnd-bbww.org

Freshford Singers Christmas concert

Join us for our Christmas concert to be held at **11am, Saturday 7 December** at St Peter's Church, Freshford. Admission is FREE but a collection will be held for the MND Association. The Choir (of 30 people) would be pleased if you would join us afterwards for seasonal refreshments in the Old Bakery.

This year's Christmas programme includes pieces ranging from mediaeval to modern 21st century carols from diverse sources and composers including Britten, Chilcott, MacMillan, Mathias, Rutter, Walton and Wight. We hope you can join us!

MND Association AGM streamed via web

This year, for the first time, the Association's AGM was streamed live online for people who were not able to attend. Viewers were able to type in live questions to speakers during the meeting from the comfort of their homes.

If you missed it, you can still watch the AGM online at:

<http://www.mndassociation.org/news-and-events/Features/AGM+and+Annual+Conference+live+streamed>

Bleadon Sugarcraft Show

Don't forget to come along to the annual Bleadon Sugarcraft Show – they have chosen the MND Association as their charity of the year and we'll be there with an exhibition stand to raise awareness of MND, and possibly to sample some sweet treats!

The show will be held at the Winter Gardens in Weston-super-Mare on **Saturday 7 December** from 10am to 15.30. There will be sugarcraft equipment and

cake-top decorations for sale and demonstrations throughout the day.

Items for sale

Wheelchair accessible vehicle

Fiat Doblo (Feb 2008), 1.9l diesel, 26,000 miles on the clock. **£5,000**

Two profiling beds 3' wide and 7' long made from beech and aluminum. Can be used as two singles or as a double (both sides still work independently). Manufactured by Volker. Owners paid £5,500 new but would accept **£1,200**.

A Wessex VM36 through the floor lift, which can be operated either from within the cab or from the outside, on either floor. Free to anyone who is prepared to pay the cost of removing the lift from its current position and making good the floor (approx. **£1,500 – 2,000**) and for the cost of installation in their own home.

For further information about any of these items, please phone 01380 830537.

Please note: we cannot accept responsibility for the condition of items advertised. Arrangements for collection of items of sale should be made directly between the buyer and seller. You are advised to seek advice from any necessary health care professionals and the manufacturer as to the items suitability and health and safety requirements.

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<https://twitter.com/mndbbww>

Like us on Facebook 

<https://www.facebook.com/mndassociation.bbww>

BBWW group contact details

Please use the contact details below to get in touch with your local Bristol, Bath, Weston and Winsley MND team.

Chair: Andrew Grundy andrew@mnd-bbww.org
Regional Care Development Advisor: Hilary Fairfield Tel: 01373 826289; email: hilary.fairfield@mndassociation.org
Secretary: Sue Paulley 45 Charlton Road, Keynsham, NE Somerset, BS31 2JG Tel: 0117 9376050/0117 7987233; email: sue@mnd-bbww.org
Volunteering Development Coordinator (South West): Lucy Etheridge Tel: 0845 3731839/07831 098365; email: lucy.etheridge@mndassociation.org
Treasurer: Heidi Frydman 4 Brayne Court, Longwell Green, Bristol, BS30 7DS Email: treasurer@mnd-bbww.org
Fundraising: Agnes Williamson agnes@mnd-bbww.org
Publicity Officer: Jon Wellington jon@mnd-bbww.org
Newsletter Editor: Becca Ramsden becca@mnd-bbww.org
Digital Media Officer: Gareth Weaver gareth@mnd-bbww.org
Bristol and Weston Support Meeting Co-ordinator: Ray Hulbert MBE 21 Eden Grove, Bristol, BS7 0PQ. Tel: 0117 9755492; email: ray@mnd-bbww.org
Campaign Coordinator: Elane Retford elane@mnd-bbww.org
Winsley Group Organiser/AV Co-ordinator: Daphne Cox Bede House, 175b Ashley Lane, Winsley, Bradford-on-Avon, BA15 2HR Tel: 01225 868224; email: daphne@daffers.org.uk
Association Visitor Helpline (BBWW Group) 07516 023675

If you would like to talk with someone about motor neurone disease please contact our MND Connect team on **08457 626262** or email mndconnect@mndassociation.org.

You can also visit our forum online at <http://forum.mndassociation.org>

A special thank you to our friends at Zurich Insurance plc for printing this newsletter for us free of charge



We would like to keep in contact with you about the important work we do. If you do not wish to receive further information please contact sue@chartax.biz or write to Bath, Bristol, Weston and Winsley Group, c/o MND Association, PO Box 246, Northampton, NN1 2PR.

Disclaimer: The views expressed in this newsletter are not necessarily those of the MND Association. The products and services mentioned or promoted should not be taken as recommendations by the Association, who cannot be held responsible should any complaint arise.