

### A note from the editor



Dear readers, in 2015, we will be bringing you a 'note' from different members of our committee to introduce each edition of the newsletter. As editor of the newsletter, I thought it only fair that I went first! MND has been hitting the headlines a lot over Christmas and the New Year, with the release of 'The Theory of Everything', a love story about Stephen Hawking's first marriage. The film has touched the hearts of people all around the world and has raised a huge amount of awareness of MND. Although a difficult viewing for people affected by MND, it is a beautifully made film with some superb acting from the lead roles, and if you haven't already seen it, I recommend you do.

In this edition, you'll read about the latest news from the MND clinic at Southmead Hospital, see an introduction from Neil Drinkwater who is new to the MNDA and learn about the many fundraising and social events we have planned for 2015.

We thank you for your continued support in helping us to raise awareness of MND. If you can think of anyone who is looking for a voluntary role, we are always looking for more help and would welcome anyone who is able to give up some of their time. In particular, we are short of Association Visitors in the Bristol area, so please do help us to spread the word and get in touch if you can think of anyone who might be interested.

 <https://twitter.com/mndbbww>

 Like us on Facebook <https://www.facebook.com/mndassociation.bbww>

**Becca Ramsden**

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### Plea for more Association Visitors in the Bristol/Bath area

Association Visitors (AVs) are at the heart of what the MNDA does and we desperately need more in our area. AVs provide support and information to people with MND, their families and carers. If you know anyone local who might be interested in this role, please encourage them to contact us. There is a wealth of information on the training provided, support given, case studies and a comprehensive list of FAQs on the MNDA website for people looking to make a difference.



At the link below, you will also find an information pack, full description of the role and an application form to fill out. We urge you to take a look to find out more and get involved, if you can.

<http://www.mndassociation.org/get-involved/volunteering/association-visitors>

## Welcome to the MNDa, Neil

Thank you for the opportunity to introduce myself. My name is Neil Drinkwater and, as you may be aware, I have recently been appointed Regional Care Development Adviser for the Bristol and West (formerly West of England) patch.

I have spent the last five years working in Bath and North East Somerset supporting carers and working closely with health and social care professionals to develop and improve the way carers are recognised, involved and supported. While at Bath and North East Somerset Carers' Centre, I have worked at the Royal United Hospital supporting carers through their journey from admission to discharge, and worked alongside a number of local organisations and charities to achieve this. I have academic qualifications in psychology and medicine, and conducted my training across the south west before settling with my family to live and work in the beautiful city of Bath.



I am delighted to be joining the MND Association. Though I am only in my second week, in that short time I have been able to meet many of my new colleagues at the head office in Northampton and have also just begun meeting local representatives from branches in the area. Already I am impressed by the dedication and compassion that the staff have for people who are living with MND, and also their families and carers. Similarly, I have been captivated by the energy and 'gung ho' passions of the many fundraising activities I have been hearing about and I feel very lucky to be working with alongside the Bristol, Bath, Weston and Winsley branch. Moreover, I am looking forward to meeting as many of you as possible in the near future and to support and serve your future fundraising activities in any way I can.

Best wishes to you all, **Neil Drinkwater**

## Latest news from Bristol MND Care Centre

As from January 2015, Sally Darby (Specialist Dietician, North Bristol NHS Trust) will be in attendance at our MND clinics and is happy to see people to offer advice on your nutritional status as well as review your dietary intake, especially if you are experiencing difficulties in maintaining weight. Sally can also offer advice if you are considering having a gastrostomy tube inserted (PEG or RIG). Dr Merrison, the Neurology Specialist Registrar, or I may also advise you to see Sally while you are in clinic if we feel this would be helpful for your care. At present there is no need to book an appointment with Sally, but please do highlight to clinic staff if you would like to see her so this can be arranged. By having Sally in clinic, this means people will now have to attend fewer hospital appointments, as previously people had to attend a separate appointment to see a dietician.

In other news, we should have our patient information leaflet on the MND Care Centre published this spring as well as a webpage on the North Bristol NHS Trust website. A questionnaire should also be offered shortly to people attending the clinic in order for us to receive feedback on our service – we welcome all comments from people with MND as well as their families and carers.

**Helen Madden**, MND Care Coordinator, Southmead Hospital

## Off to the panto they went...

Well, it's that time of year again, and following the fun had by all at last year's panto trips, we organised two more trips to the Bristol and Bath pantomimes in January. Hear about how our theatregoers got on, in the articles below.



With an all-star cast of Dani Harmer (Tracey Beaker) as Cinderella, Melanie Walters (Gavin & Stacey) as the Fairy Godmother, hilarious local comedian Jon Monie as Buttons, and David Ball and Byron Mondahl playing the Ugly Sisters, the Bath performance was sure not to disappoint.

Two of us – people living with MND and their carers and four volunteers were due to attend Cinderella at the Bath Theatre Royal, but unfortunately, two had to cancel on the day and another was only able to stay to the interval. However, the four volunteers and Denise from the Winsley group were able to enjoy the performance and a carer and my husband took two of the spare seats to save wasting the tickets.

When the panto finished, we found that the lift had stopped working so it looked as though Denise might have to stay the night! Fortunately, four theatre assistants came to her rescue and carried her in her chair down the front flight of stairs – much to the amusement of all.



**Ruth Noakes**

On 3 January, 11 of us braved the elements to go and watch the matinee performance of Dick Whittington at the Bristol Hippodrome. The cast included Ashleigh and Pudsey, who won Britain's got Talent in 2012, as well as Brenda Edwards who entered the second series of the X Factor. The Pantomime was family-friendly fun, and was thoroughly enjoyed by all.

**Maria Baker**

## Swing your sticks and raise some cash for the MNDa

We are very pleased to announce a special golf tournament at Filton Golf Club, Bristol, on **Saturday 18 April** – save the date!

The Club has very kindly agreed to waive their Green fees and provide access to their Club House free of charge for all participants. From 8 am, teams of two players can partake in a round of golf for just £10 – all in aid of the MNDa; those of you who play regularly will know that this is a steal!



We will be holding a raffle both before the event and on the day; and in the evening, there'll be a dinner with an auction at the Club House. Please help us to spread the word about what is sure to be a memorable day and evening. Please contact Ray Hulbert

(contact details on back page) for further information.

### 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. These informal gatherings are an opportunity to catch up with friends and meet new people over a cuppa and some



### Forthcoming meetings – Bath & Winsley

This group meets on the first Wednesday of the month, **14.00–15.30** (doors open from 13.30)

**4 March** – Speaker: Ruth Noakes (Accessing Information), Winsley Church Hall, Winsley

**1 April** – Speaker: Helen Madden (Bristol MND Care Centre Coordinator)

From April, the meetings will be held **Foxhill Community Centre, Hawthorn Grove (off Entry Hill), Combe Down Bath BA2 5QD**

Contact: Ruth Noakes  
01225 316538; [ruth.noakes@homecall.co.uk](mailto:ruth.noakes@homecall.co.uk)

### Bristol & Weston Group

This group meets on the last Saturday of the month at St Peter's Hospice, Brentry, Bristol, BS10 6NL, **14.00–16.00**

**The next dates are: 28 February, 28 March, 25 April 2015**

Contact: Ray Hulbert  
0117 9755492; [ray@mnd-bbww.org](mailto:ray@mnd-bbww.org)

cake.

The Bristol & Weston group continues to be run by Ray Hulbert – see details of forthcoming dates in the box. The Winsley & Bath group has recently been taken over by Ruth Noakes.

The group will continue to be held in Winsley for the March catchup but will relocate to Bath from April (see box for further details). All people living with MND and their carers are welcome to come along to these meetings.



## The Theory of Everything

The Theory of Everything is a biographical romantic drama inspired by the book 'Travelling to Infinity: My Life with Stephen', written by Stephen's first wife Jane. We were pleased that the Cineworld chain of cinemas gave the MNDa permission for local branches and groups to

make collections at the screenings on 2 January. We went along to Cineworld, Hengrove in Bristol donning our MNDa T-shirts and raising awareness and funds for MND. It was a quiet afternoon at the flicks, but even if we reached only a handful of people, it was well worth it. Several of us from the BBWW group have been to see the film and thought it was excellent. Although tough to watch for anyone affected by MND, the acting was fantastic and Eddie Redmayne did a great job of portraying Professor Hawking. The film has been hailed a great success, and we hope that the widespread appeal of the love story will spread awareness of MND across the country.

## Condemned to Silence – a positive response from number 10

Prime Minister David Cameron has vowed to support people living with MND following the All-Party Parliamentary Group on MND's report on poor access for communication aids.

Around 50 MPs were represented at the launch of Condemned To Silence; they heard the shocking findings of the report, which took evidence from nearly 1,700 people living with or affected by MND. Madeline Moon MP attended the launch and then raised the issue at Prime Minister's Questions the following day.



In response, David Cameron said, "[MND] is the most appalling, debilitating condition, and it's very, very difficult for families to cope with, so I will certainly look at the report that she has produced, and make sure that the proper meetings are held with the Department of Health so that everything we can do to support these people, and allow them to communicate with their families up until the last moment, can be done."

### Could you help us to save costs?

Would you like to receive your BBWW group newsletter by email instead of in the post?

Please email me (Becca Ramsden: [becca@mnd-bbww.org](mailto:becca@mnd-bbww.org)) with your contact details if you would like to join our e-mail list and receive an electronic rather than a paper copy of the newsletter.

### BBWW group contact details

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

Chair: <b>Andrew Grundy</b> <a href="mailto:andrew@mnd-bbww.org">andrew@mnd-bbww.org</a>
Regional Care Development Advisor (Bristol & West): <b>Neil Drinkwater</b> Email: <a href="mailto:neil.drinkwater@mndassociation.org">neil.drinkwater@mndassociation.org</a>
Secretary: <b>Jon Wellington</b> <a href="mailto:jon@mnd-bbww.org">jon@mnd-bbww.org</a> Tel: 07887 387724
Volunteering Development Coordinator (South West): <b>Angela Lea</b> Tel: 08453 751834/07887870473; email: <a href="mailto:angela.lea@mndassociation.org">angela.lea@mndassociation.org</a>
Treasurer: <b>Heidi Frydman</b> 4 Brayne Court, Longwell Green, Bristol, BS30 7DS Email: <a href="mailto:treasurer@mnd-bbww.org">treasurer@mnd-bbww.org</a>
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Bristol & Weston Support Group Coordinator: <b>Ray Hulbert MBE</b> 21 Eden Grove, Bristol, BS7 0PQ. Tel: 0117 9755492; email: <a href="mailto:ray@mnd-bbww.org">ray@mnd-bbww.org</a>
MND Care Coordinator: <b>Helen Madden</b> North Bristol NHS Trust, c/o Dept. of Neurology, Gate 10, Level 6 – Brunel Building, Southmead Hospital, Bristol, BS10 5NB Tel: 0117 414 0803; email: <a href="mailto:Helen.Madden@nbt.nhs.uk">Helen.Madden@nbt.nhs.uk</a>
Winsley & Bath Support Group Organiser: <b>Ruth Noakes</b> Tel: 01225 316538; email: <a href="mailto:ruth.noakes@homecall.co.uk">ruth.noakes@homecall.co.uk</a>
Association Visitor Helpline (BBWW Group): <b>Heather Watson</b> 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](mailto: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 [becca@mnd-bbww.org](mailto:becca@mnd-bbww.org) or write to Bath, Bristol, Weston and Winsley Group, c/o MND Association, PO Box 246, Northampton, NN1 2PR.

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