

Note from the Chair

So here is another new year. Looking back on 2013 I think we can be reasonably satisfied with our work, not least our fund raising efforts that see our finances looking healthier than the same time last year – thanks to all that dedicated their time and/or contributed financially.



I hope all are weathering the constant rain without too much trouble. My house certainly sprang a couple of leaks that saw me carrying out some emergency pointing; but, in comparison to what some have suffered, it was a minor inconvenience. For those with people living with MND in the house it could be quite a worry – so please don't hesitate to contact us if help is required.

We continue to use the Lottery money to support the support groups, for which the latest excursions were the visits to the pantos in Bristol and Bath; read all about them below.

And if I might be allowed to say again that one issue that is high on our agenda is the need to recruit more Association Visitors (AVs) to support people with MND. Please help us by thinking about how you might help to identify suitable candidates for this crucial role.

Andrew Grundy

MNDA at the Bath Christmas Market

We were lucky enough to be allocated a chalet again by Bath Tourism at the Bath Christmas Market; this time we were there for the day on Tuesday 10th December. Someone was smiling on us because the day was fine, and although crisp, wasn't

too cold and the rain stayed away. We wondered just how busy a Tuesday would be, but we needn't have worried. It wasn't the mad crush of the Saturday that we had in our first year at the market, but there was a steady stream of keen visitors who we enticed to our stall. The market seems to go from strength to strength and Bath Council stated that they estimated it brought something of the order of £20 million into Bath. What is certainly noticeable is that visitors come from far and wide.



The objectives for the day were to raise awareness of MND and to raise funds to support people with MND. As part of the fund raising we ran a Tombola, and a number of local shops and stores very kindly donated handsome prizes that made it a success, namely: Bath Aqua Glass, House of Bears, Lakeland, Pia, Miles Mann, Topping Booksellers, Bath Compact Disc, Shannon, Melanie Giles, Raisin Fine Wines, Prior Park Garden Centre, M&S, Sainsbury's, plus lots and lots of private donations (thank you everyone). In addition, we sold various MND items including Christmas cards (we even had a

few MND Christmas puddings left over from last year – yes they were still well within the sell-by date).

Many volunteers worked on the stall in shifts during the day to make it a success, from the opening at 10.00 until close at 19.00 that night and it was busy from start to finish. Everyone deserves a big thank you, and everyone who participated enjoyed themselves.

All in all a very good day, helping to raise awareness of MND, and raising funds of just **over £760** (again I descended into Lloyds bank with a very heavy bag of coins – and once again I have to say that the staff were very accommodating in helping me to count, sort, and bank the cash).

Thanks again to all the helpers, and we are hopeful we can repeat the success again next year.

 <https://twitter.com/mndbbww>

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

Fabulous Fundraisers!

Thank you to all of you who have braved the awful weather over the festive period and raised some much needed funds for people with MND. In addition to the efforts of team BBWW at the Christmas market, a team of eight high-spirited volunteers packed bags for hordes of Christmas shoppers at Marks & Spencer's in Bath on Sunday 22 December. With bundles of stamina, the troopers were on their feet for three hours and raised a fantastic **£657** for their efforts!

Earlier in December, we attended the **Bleadon Sugarcraft Show** at the Winter Gardens, Weston-super-Mare. As the official charity for the day, volunteers

stocked a table with cards, puddings, cakes and treats to sell. The hand-painted BBWW Gromit (pictured) went down well and helped to raise **£218** over the course of the day.



Singing for MND

On a Saturday morning in early December, St Peter's church in Freshford, just southeast of Bath, was packed to overflowing. The attraction? The Freshford Singers' annual Christmas concert and the knowledge that there would be a collection for the MND Association. Alistair the Optimist (Alistair Banks who died of MND a year ago) was the son-in-law of long-time residents of Freshford and was well known in the village.

It was a wonderful programme of Christmas music from all parts of the world - familiar and totally unfamiliar. Bernard Wright was the conductor and the Reverend Jeremy Wordsworth was the 'compere' for the evening. Everything combined to make a very happy and enjoyable start to the Christmas season. And the collection raised **£850!**

Hugh Delap

Oh yes they did!

On Thursday 9th January, 17 people went to a matinee performance of the Bath pantomime - Peter Pan. There was a mixture of people with MND and their carers and several Winsley group helpers. Four came in their wheelchairs and the theatre made it very easy for disabled people to reach their seats. Now we have done it once we may try and go again in the future, knowing how easy things were.

Everyone enjoyed the afternoon and ice creams were ordered for the interval.

We do hope to have another outing when the weather improves and hope that those who were unable to come to the pantomime may be able to join us.



Weston-super-Mare has been suggested for a blow on the promenade before refreshments in the elegant restaurant on the pier, passing the 'amusements' on the way!

Ruth Noakes

A few days earlier, 11 people attended the MND Bristol outing to Cinderella at the Bristol Hippodrome. It was lovely to meet some familiar faces and it is particularly good for Pam and Christine to meet each other, as they had previously only been email pals.

The staff at the Hippodrome were very supportive and the disabled access was

negotiated safely and securely with their assistance. The pantomime was all singing, all dancing and non-stop laughter. The sets were dazzling and costumes were the best we had ever seen. Louie Spence was energetic, Suzanne Shaw was the perfect Cinderella and Andy Ford was a big hit as Buttons. The Ugly Sisters were terrific and their costumes were incredible. Prince Charming was splendid.

The sets were dazzling and everyone loved the brilliant 3-D action in the second half, involving Buttons, the Ugly Sisters and some wonderful ghosts, demons, bats and spiders, which, thanks to the free special glasses provided, and the ghoulish scary antics, generated lots of squeals from the audience.

This was the best Pantomime I have ever been to, thank you MNDa BBWW.

Monica Dower

The rumors were true!



Our avid readers will remember there was a rumor of a visit from Saint Nick for the good people

of Bristol who attended the group's Christmas party spectacular at Eden Grove on 14 December. As you can see from the photo, Darryl Collins, was the star of the show, taking on the role of Santa, and gave everyone a present to take away. On top of that, there was plenty of food and drink and party games galore – a good time was had by all!

Avoiding admission to hospital

Every winter (and this year is certainly no exception) there are numerous news reports about the pressures on A&E departments and hospital beds. Whilst most people with MND would not want to go into hospital unnecessarily, the health services are also very keen to make sure that people take steps to reduce the risks that they face in the winter, so that they are less likely to need hospital care.

Information from hospital statistics show that there are three main reasons why people with MND may be admitted to hospital. These are:

- As a result of slips, trips and falls
- Breathing problems – e.g. chest infections
- Because the people who usually provide care and support within the home (whether family members or paid carers) are no longer able to do so due to illness, stress or lack of resources.

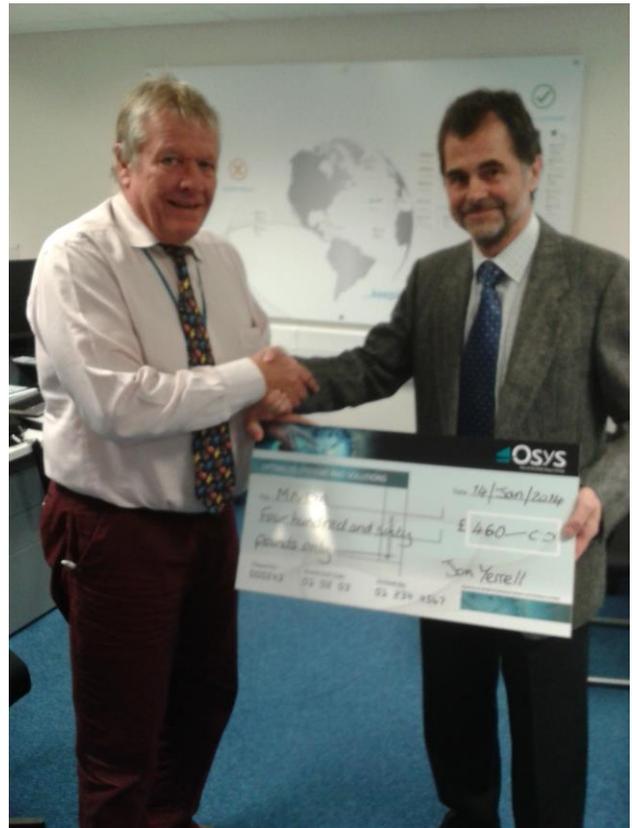
If you have any questions, please contact Hilary Fairfield, at hilary.fairfield@mndassociation.org

OSys

You may not have heard about OSyS; I hadn't until I received an e-mail from them saying that they had spent the year fund raising, we were one of their chosen charities, and could we turn up on 14th January to receive a cheque – not a bad introduction.

Well OSyS are a branch of Rolls Royce based in Bristol. I'm afraid that if they told us really what they do they would have to shoot us (Top Secret Stuff) so going along to their office was an interesting one – where security is obviously high priority. But that didn't detract in any way from the event they had organised. We were made

very welcome, all OSyS staff were gathered to take a look at all the fund raising activities they had undertaken during the year (quite a list), and then each sponsor of a particular charity presented a cheque to their chosen charity. The charity representative was invited to say a few words about their work. There were five charities represented and each one had an inspiring story to tell. I won't list all the charities, but I will say that the star of the show was a guide dog called Des.



Andrew collected a cheque for £460 for MND from this event, and has since received another cheque for £140 from Jon Yerrell, our sponsor at OSyS who raised these funds through a slimming 'competition' at his local pub – I didn't ask about the precise rules for this event. Jon lost his brother to MND a few years ago and was keen to support our charity. The photo shows Jon presenting the cheque. So it is thanks to OSyS, and in particular Jon, for their fund raising efforts.

News from the MND Association

The MND Association have launched a new tool to help GPs diagnose MND earlier. We have been working with The Royal College of General Practitioners (RCGP) on an early diagnosis of MND and a new Red Flag tool which will help reduce inaccurate referrals and therefore reduce the time to diagnosis.

Further information and a presentation on the new tool can be found at:

<http://www.mndassociation.org/professionals/for-gps/Red%20Flag>

Football v MND

Mark Maddox lived for football but now he's dying. He has motor neurone disease (MND) and it's started to affect the way he walks and talks. He knows it won't be long before he's in a wheelchair. Mark's run marathons and jumped out of aeroplanes to raise awareness, but time is running out and he needs your help. As a player Mark made 300 appearances. He needs your help to make 300 more, before he dies from MND.

Get your team to include Mark's Football v MND poster in their match day



programme. You don't even have to follow a team to get involved: take Mark's Crossbar

Challenge and share your video with us. Further details:

<http://www.mndassociation.org/news-and-events/Football%20v%20MND/index>

Glow in the park

Fancy a challenge for the New Year? Brighten up those dull, winter evenings and 'Glow in the Park' in a series of 5k and 10k runs! Set in parklands throughout the UK - Glow in the Park offer a safe environment to experience the excitement of running in the dark!

Come to the event dressed in all your finest hi-viz - bring head torches, light sticks and flashing necklaces...anything you can think of to help you stand out in the crowds!

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

7 February 2014

7 March 2014

4 April 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

22 February

29 March

26 April

Contact: Ray Hulbert

0117 9755492

ray@mnd-bbww.org

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
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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.

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