

# Bristol, Bath, Weston & Winsley group

## Summer newsletter 2014

[www.mnd-bbww.org](http://www.mnd-bbww.org)



### Note from the Chair

Hope you have had the opportunity to enjoy some of our good weather. We were particularly fortunate to have glorious sunshine for the Summer Festival which was a blessing as all the hard work that had gone into planning the event was repaid – thanks again to all who helped make it a great success.



I'm also struck by the endurance of many of our supporters: '500 mile cycling', 'zooming across the UK', '7 marathons in 7 days' — read all about it and marvel at these intrepid volunteers who raise the profile of MND and significant funds in the process.

And finally, the Frenchay hospital has moved to Southmead, together with the MND Care Centre. After a few teething problems we seem to be settling into a routine in a very impressive new state of the art facility. Our care coordinator Helen Madden introduces herself below.

*Andrew Grundy*

### Summer festival success!

There was a fantastic buzz about Eden Grove on Global MND Awareness Day (21 June 2014). Bunting was erected, bouncy castles were inflated and stalls aplenty were set up for the day, all to raise



awareness of MND and the work that we do at the MNDA. The public turned up in force and spent their money on cakes, books, toys, bottles and raffles, and were rewarded with an array of wonderful music from the Welsh Wizard organist, Filtones choir and Croft End Silver Band. Meanwhile, outside, the battle re-enactment company (pictured) swung their swords at each other and put on a really good show for the spectators.

More photos of the day can be found at: <http://ow.ly/zAW2e>. A huge thank you to all of you who helped out or contributed to the day. Most of all we'd like to thank Ray who worked tirelessly for months organising the whole event. Pictured below are VIP guests Mary Prior, Lord Lieutenant of Bristol, and John Prior along with Gareth, Maria, Ray and Andrew from



the BBWW group, alongside Rhian Priest (Head of the BTEA).

We are very pleased to announce that a whopping **£2,400** was raised on the day. Equally as important, we raised awareness of MND – lots of people signed the MND charter (including the local MP) and signed up to our mailing list. In fact, the event was such a success that we're doing it all again next year – mark your diaries for **Saturday 20 June 2015!**

## Bristol MND Care Centre relocates

The Bristol MND Care Centre has moved to the new Brunel building at Southmead Hospital, North Bristol NHS Trust. The opening of the Brunel building (pictured below) means there are now a wide range of local and regional centres of healthcare excellence based on one site.

The MND clinic continues to be held on Tuesday afternoons and is based at gate 36, level 1 (ground floor) of the Brunel building, next to the League of Friends' cafe. There are volunteers at the main hospital entrance to direct people who are coming for the first time.



Association Visitors from the MND Association will also be attending the clinics from July to help direct people, provide information and arrange any ongoing support that people may need.

At your first appointment in the clinic you will be seen by Dr Andria Merrison (Consultant Neurologist & Director of the Bristol MND Care Centre). For further appointments you will be seen by Dr Merrison and/or a Specialist Registrar in Neurology. We work as a multi-disciplinary team to enable people to receive help from a range of professionals. We also run a joint clinic with the Respiratory team at the Bristol Royal Infirmary Sleep Unit to assist people with breathing difficulties.

Helen Madden (pictured: above right) is the MND care co-ordinator and the main

point of contact within the care centre. Her role is to provide support and information as well as to ensure people with MND receive the care they need at the right time by referring to local health



and social care teams and voluntary organisations. Helen (pictured above right, alongside Dr Merrison) will be in attendance at the clinics and can also be contacted by telephone and e-mail in between clinic appointments.

New referrals to the clinic are welcome. You can be referred to the MND clinic via your local Consultant Neurologist or GP.

Over the next few months we will be finalising our information leaflet on the service and developing a webpage on the North Bristol NHS Trust website. We are also developing a questionnaire so we can receive feedback on our service from people living with MND, their families and carers, who attend the centre.

For further information please contact:

**Helen Madden**, MND care coordinator

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E-mail: [Helen.Madden@nbt.nhs.uk](mailto:Helen.Madden@nbt.nhs.uk)

Website for North Bristol NHS Trust: <http://www.nbt.nhs.uk/>

## Zooming across the UK

While on the subject of care centres, an inspirational fundraiser from Manchester paid the new care centre at Southmead a visit, as part of his tour around the UK to raise money for MND. Mark Bowers zoomed across England, Scotland, Wales and N. Ireland visiting all the MND care centres on his trusty motorbike. Battling the elements and completing some serious miles each day, Mark started his journey on Global MND Awareness Day. My family and I (pictured below) welcomed Mark at Southmead Hospital, and signed his bike on which he had attached a map of his journey.

Congratulations to Mark on a fantastic tour, during which he had a pint with Prof. Steven Hawking, met many more people



involved with the MNDA, and raised **over £5,000** to help people living with MND. You can view further photos at Mark's Facebook page <https://www.facebook.com/mndgbmotorcycletour> and JustGiving page [www.justgiving.com/mndgbmotorcycletour](http://www.justgiving.com/mndgbmotorcycletour).

## 500 miles in 5 days for MND

From motorbikes to push bikes – staff and 6th form students from the Bristol Technology and Engineering Academy (BTEA) donned their lycra and rode over **500 miles** in just **5 days** in July to raise

money for research into motor neurone disease. The team (pictured below) set off from Bristol on 7 July and pedalled at top speed to take in Reading, Bedford, Milton Keynes, Silverstone, Daventry, Birmingham, and Worcester, and then back to Bristol, where they finished on Friday 12 July.



The superb cyclists have raised in the region of **£7,500** to donate to our group. The whole academy is incredibly proud of the team. The Bristol Evening Post printed an almost full-page feature in the weekend edition of 11 July. The BBWW group would like to extend a huge thank you to all of the team for such a super effort and valuable funds raised.

## Charity barn dance

A big thank you goes to Sonia Fox and team for organising a very successful barn dance to raise funds for the MNDA back in May. They sold an impressive 120 tickets for the event and raised a whopping **£1,522.38!**

Sonia also completed the 3 peaks challenge for MND raising a **further £1,400!**

**Could you become an Association Visitor (AV)? We are in need of more AVs to support people with MND in our area. Find out what's involved at: <http://www.mndassociation.org/get-involved/volunteering/association-visitors>**

## 7 marathons in 7 days!

Continuing with the theme of fantastic fundraisers, Jason Smith and team completed an impressive 7 marathons in 7 days at the end of May. Each day, the team raised money for a different charity, and on the 3rd day they chose to support



the MNDA. Gareth from the BBWW group, along with Bill Doody, joined them and ran the marathon on the MNDA day from Bath Cathedral to Glastonbury Tor. Pictured above (L to R) are the runners: Bill Doody, Jason Smith, Rachel Smith, Gareth and Darren Abbotts. An associate of the Brighton MNDA group, who happened to spot the team running through Bath, is pictured alongside them. Gareth Starr was also part of the challenge team but he started earlier in the day as he was suffering from the day before.

Gareth (Weaver) also joined the team for the final day of their event when they took part in the Mendip Challenge – a 30 mile route from Wells to Weston-super-Mare.

Clare Passrellii from the Winsley group deserves a special mention here as she followed the 7x7x7 team around for the whole week as their nurse/physio. Congratulations to all of the runners and their support teams, and a big thank you for raising lots of money and awareness – the group raised **over £1,000** for the MNDA.

## Another festival in aid of MND funds

On Sat 19 July, The Old Crown in Kelston played host to another spectacular fundraising day for MND. Having battled through some horrid weather at the start of the day, the sun came out and the party started in earnest in the afternoon. There was Morris dancing, live music, a cider festival, raffles and an auction. The ukulele band of 'freak bitton' also played. The day was a huge success with **over £1,800** raised. Thank you to Dean and everyone else who was involved in the event.

### \*\*\*Dates for your diaries\*\*\*

On **Friday 19 September** there will be a 'Friends Meeting' to discuss plans for future MNDA events. This will be an open event and all are welcome to attend. Come along to Eden Grove (Eden Grove Church, Horfield, Bristol BS7 0PQ) at **10 am** to have your say and share some ideas.

Following their successful appearance at the MND festival, the **Croft End Silver Band** will be putting on a special charity concert in aid of the MNDA on **Sunday 26 October**. Come along to Eden Grove Church at **3 pm** to watch the band and enjoy a cream tea in the interval. Tickets are £6, with all proceeds going to the MNDA. Please spread the word among friends and family.



<https://twitter.com/mndbbww>



Like us on Facebook

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

## Winsley group trip to Weston

On 22 May, 11 people from the Winsley support group took a trip to Weston-super-Mare. We were joined briefly by Hilary Fairfield and later by three extras from MND families.



The weather was a bit blustery and damp and our picnic lunch had to be eaten on the sheltered side of the pier. We abandoned a walk along the promenade and decided to head straight to Tiffany's restaurant for afternoon tea, using the land train to take us most of the way.

We had a struggle to get Denise through the amusements (!) but eventually we all enjoyed a cream tea and/or ice cream. The restaurant sticks out over the sea and one or two braved the walk outside.

Everything went fairly smoothly and I think all really enjoyed it. Of course, as we made for our homeward transport, the sun came out!

**Ruth Noakes**

### 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** group meet on the 1<sup>st</sup> Friday of the month at Winsley Church Hall, BA15 2LH at **13.30-15.30**

**The next dates are: 5 September, 3 October and 7 November**

Contact: Daphne Cox  
01225 868224; [daphne@daffers.org.uk](mailto:daphne@daffers.org.uk)

**Bristol and Weston area** group meet on the last Saturday of the month at St Peter's Hospice, Brentry, Bristol, BS10 6NL at **14.00-16.00**

**\*\*NB. There will be no meeting on 30 August\*\***

**The next dates are: 27 September (Speaker: Helen Madden, MND Care Centre) and 25 October**

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

### A big thank

**you** goes to the Bath branch of Waitrose for choosing us as one of their charities for April. We received a cheque for £460 from their Community Matters scheme. Thank you too to all of you who shopped there and popped your green tokens into our box!

## BBWW group contact details

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

Chair: <b>Andrew Grundy</b> <a href="mailto:andrew@mnd-bbww.org">andrew@mnd-bbww.org</a>
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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 Group Organiser/AV Coordinator: <b>Daphne Cox</b> Bede House, 175b Ashley Lane, Winsley, Bradford-on-Avon, BA15 2HR Tel: 01225 868224; email: <a href="mailto:daphne@daffers.org.uk">daphne@daffers.org.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,

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