

Bristol & Bath Group

Newsletter – Summer 2015

www.mnd-bbww.org



Supporting local people affected by
Motor Neurone Disease (MND)

A note from the Secretary/Campaigns Coordinator



I've been asked to write the introduction to the summer newsletter as I had the privilege of attending the association's parliamentary reception in June – more details of which can be found below. Also in this issue, details of all the other events we have had in the area including our annual summer fayre in Horfield, which was a huge success.

As the campaigns contact (and secretary!) for the group, I can't let this opportunity go by without urging you all to get in contact with your MPs and councillors about the various campaigns that the MNDa is running. Please check out the MNDa campaigns homepage (www.mndcampaigns.org) for more details of the latest campaigns. This is particularly important if you have a new MP representing your area since the general election, as I know many of you have. While the association has made great strides in raising awareness of the disease and the MNDa over the last few years, there is still a lack of knowledge of MND among certain decision-makers, and the more that we can push them to take action, the better the care and support available for people living with MND and their carers.

If anyone would like to speak to me about campaigns or how they can get involved, feel free to contact me anytime.

Jon Wellington
jon@mnd-bbww.org

Fantastic day out at the MNDa Summer Festival!

Saturday 20 June saw our second annual festival take place at Eden Grove Methodist Church in Filton, Bristol. Held during MND Awareness Month, we were pleased to see some new faces come along, many of whom

had been affected by MND and were looking to find out more about what we do as a group, and seeking support among new friends.

We were treated to an array of entertainment over the course of the day, a highlight of which was the display from the battle Re-enactment Society (pictured). The 'Vikings' fought gallantly much to the delight of the gasping crowd – the children among



them were particularly pleased to see the fallen rise again at the end of the show! Thanks to Bristol City Council (Dovercourt Road depot) for providing the safety railings, which were very useful on the day.

Live music was provided by the Croft End Silver Band and the 'Welsh Wizard' organist, both of whom played brilliantly to entertain the audience. A huge thank you to Ray and all his fantastic helpers who organised the day and helped it all run smoothly. We were pleased to come away with £679 profit!



<https://twitter.com/mndbbww>

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

Could you be an AV?

We desperately need more Association Visitors (AVs) in the Bath and Bristol area. AVs provide vital support for people living with MND. To find out more, and if you think you could help, please click on the link below. Full training is provided.

www.mndassociation.org/get-involved/volunteering/association-visitors

On yer (fat) bike

We were delighted that Tom Vincent and family came to meet us at the MNDa summer festival. Tom brought along his fat bike on which he is currently cycling across Iceland to raise funds for the MNDa.



Along with his mate, Jim Gardiner, Tom will be taking on the daunting task of cycling unsupported coast-to-coast across Iceland, covering over 500 km across bumpy, unpredictable terrain. Good luck to both riders; follow their progress via Tom's blog: <http://icelandicfatfun.blogspot.co.uk>.

Trip to Tyntesfield – new date

The trip to Tyntesfield National Trust property and gardens has been postponed to Friday 14 August. Please get in touch with your AV or Maria (07974783436; maria@mnd-bbww.org), who is organising the day out, to book your place. The day out is for people living with MND and their carers/families.

MNDa Parliamentary Reception

To mark MND Awareness Month, the MNDa held a reception for parliamentarians and volunteers in Church House, Westminster. I attended on behalf of our group and can report that the day was a huge success. Around 130 volunteers from all over the UK attended – the room was a sea of blue t-shirts! – and 75 parliamentarians attended, including Charlotte Leslie MP (Bristol North West), pictured with Jon and Good Morning Britain's Charlotte Hawkins, who also attended



the event and gave a very moving speech following the death of her father from MND earlier in the year.

MNDa chief executive Sally Light also spoke and thanked all volunteers and members for all their work. David Setter, a campaigns volunteer with MND also spoke very eloquently about the challenges people like him face, and how volunteering for the association has helped him to remain positive and active.

I spoke to MPs and members of the House of Lords about the group and its activities, and the continuing need for greater awareness and availability of resources for people with MND in Bristol and Bath.

Prior to the reception, volunteers handed in the 33,360 signatures of support for the MND Charter, which seeks to increase understanding and awareness of what care for people with MND should be like. Thanks to everyone who has signed this and urged their elected representatives to do the same over the last 3 years and helped spread awareness of the rights of people with MND and their carers.

Jon Wellington

Update from Bristol MND care centre

Since our last update, there have been a few developments at the care centre. We have been fortunate to have secured funding for a second Consultant Neurologist with specialist interest in neuromuscular disease & MND, with interviews being held later this month. This is great news as it will mean we will have more MND clinics, so people newly referred to us will be seen sooner, and there will be more flexibility with follow-up appointments. We hope the successful candidate will be in place by the end of 2015 and they will work very closely with the existing team of Dr Andria Merrison and me.

We also are holding our first health and social care professional MND study day this September and applications are steadily coming in from a range of professionals, interested to learn more about MND. The study day will cover a range of topics, and we are very grateful for a few Association Visitors who will be helping on the day with all the logistics. As a care centre, we are keen to support health and social care professionals, especially those who have little experience of seeing people with MND, so will be holding

*****NEW MNDa Connect phone number*****

03457 626262

regular study days on a range of topics over the coming years.

Dr Merrison and I also attended a recent Bristol GP study day to raise awareness of MND as well as our care centre, which was well received, and we hope further raises awareness of MND and local support available to GPs.

Helen Madden

'End of life' arts project

Join the MNDa's Care Information Manager, Kaye Stevens as she talks about the MNDa's groundbreaking 'End of life guide' – how it was developed, how it is being used, and how it can support difficult conversations. Her talk forms part of a wider series of events and



activities running from 16 September to 11 October 2015 called 'When death comes: creative conversations about dying and living.' 'When death comes' is organised by Philippa Bayley, whose mother Sabine passed away from MND in 2013.

Philippa's photograph of Sabine's hand (above) and Sabine's ceramic piece 'The little bird girl' are pictured.

The aim is to provide a creative space and series of events where people can think about, talk about, and create work about dying and living, taking inspiration from Sabine's creative life. Philippa would welcome contributions from and connections to people touched by MND.



We hope you will be able to support this project by coming along to the exhibition and/or one of the events. Click on the link below to find out more:

<http://whendeathcomes.uk>

Thank you, Keynsham Ladies

Our chair, Andrew Grundy, had the pleasure of meeting the Keynsham ladies' society



'Keyring' recently to hear about how they raised a fantastic £500 for the MNDa. One initiative they came up with was asking families to fill empty Smarties tubes with 20p

pieces – a great idea for chocolate fans! Andrew is pictured being presented with the cheque by Nicole from the group.

Sally Light visits Bath support group

In May, Sally Light (Chief Executive, MND Association) came along to the Bath support group and gave a short talk about 'what's going on in the MND organisation'.

Sally spent quite some time answering questions from the attendees in a very interesting session. In addition, she presented Daphne Cox (pictured with Sally) with a 'Long Service Award'.



Support Group Info

Bristol & Weston group meets on the last Saturday of the month at St Peter's Hospice, Brentry, Bristol, BS10 6NL, **2-4 pm**

The next dates are:
26 September; 31 October 2015

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

Bath & Winsley support groups are held on the first Wednesday of the month, **2.00-3.30 pm**, at Foxhill Community Centre, Hawthorn Grove (off Entry Hill), Combe Down, Bath, BA2 5QD.

The next dates are:
5 August – Speaker Julia Frank Nutritionist;
2 September – Speaker Tom Fox-Proverbs from BANES Carers centre;
7 October 2015 – General chat and information session

Contact: Ruth Noakes, 01225 316538;
ruth.noakes@homecall.co.uk

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 or write to Bristol & Bath Group, c/o MND Association, PO Box 246, Northampton, NN1 2PR.

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Winsley & Bath Support Group Organiser: **Ruth Noakes**
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If you would like to talk with someone about motor neurone disease please contact our MND Connect team on 03457 626262 or email mndconnect@mndassociation.org.

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

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