

Dear readers,

Spring has most certainly arrived, with the longer evenings, blossom on the trees and beautiful sunshine. In this newsletter, we are pleased to report on the success of our recent charity event at Filton Golf Club; thanks to the seamless organisation, the day ran very smoothly and we raised a great deal of awareness of MND – the main purpose of the day (read a full report below). Also in this issue, we hear about other fundraising activities, a new webpage for the Bristol MND Care Centre and many forthcoming events, which we hope you'll do your best to support.

Whatever your political outlook, if you haven't done so already, please sign the MND Charter and share the link with your friends – at the time of writing, the charter had 29,000 signatures, a figure which we are hoping will hit 30,000 by election day.

We hope you are all getting out and enjoying the sunshine. With this in mind, we will be arranging a visit to Tyntesfield in June and hope as many of you as possible can make it – the gardens are beautiful at this time of year. Until next time,

Becca

Fantastic day of golf to raise awareness of MND



We are very pleased to report that the charity golf tournament at Filton Golf Club, held on Saturday 18 April to raise awareness of MND, was a huge success! Members of the club and many keen golfers from around the westcountry came to Filton to soak up the sun and challenge themselves to hit the ball straight despite the prevailing winds! The club kindly waived their green

fees for all those playing on the day and only charged £5 per golfer for a round – a huge discount. We had 50 teams of four playing on the day – a great turnout. Our team of volunteers also came along to set up the MNDa stand, sell some raffle tickets (thanks to Inez and Hazel from Eden Grove) and cupcakes, and watch the golfers tee off at the first hole





(pictured left). Attendees could also pay £1 to use the putting green and there was a prize for the longest putt.

After all this activity during the day, the club put on a delicious three-course meal in the evening, which was enjoyed by many of those supporting the day.

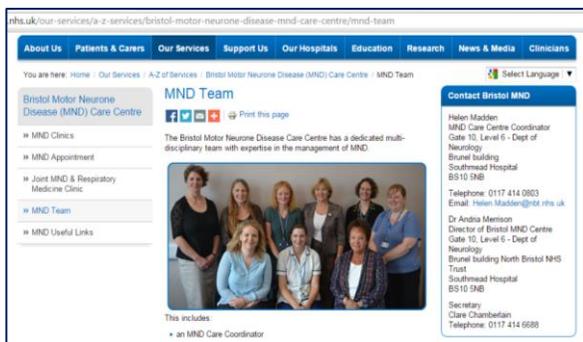
We would like to thank the club members who kindly donated raffle

prizes, Julie, and Billy and his parents who made bacon rolls for the early starters, and to all the staff in the bar and restaurant for all their hard work. We are immensely grateful to the club for putting on this event for us. In particular, our thanks go to Roy Oaten, Geoff Anderson and Geoff Endicott at the club who organised the day with cheer and expertise, along with Ray Hulbert from the BBWW group, without whom the day would not have been possible. Our gratitude also goes to Sir James and Lady Virginia Tidmarsh for supporting the dinner.

As well as spreading the word about MND, the event raised over £1500, which will go directly towards supporting people in the local area living with MND. I'm sure all those who attended will agree it was a fantastic day, and we hope to organise something similar next year...

Bristol MND Care Centre – new webpage and information leaflet

The Bristol MND Care Centre, based at Southmead Hospital in Bristol, is pleased to announce they now have a new webpage about the MND Care Centre published on the North Bristol NHS Trust website. They have also produced a new patient information leaflet, which is available for people attending the clinic.



Currently, the website has the same information as the patient information leaflet, but over time we plan to add more information to the website for both people living with MND as well as for

local health and social care professionals.

Helen Madden (MND Care Coordinator) would welcome any feedback on these initiatives. Please contact Helen using the details on the back page, and visit the link below to access the webpage.

www.nbt.nhs.uk/bristolmnd

Girls hold a cake sale in aid of MND



The cake sale was in memory of Amy's Granddad who died from MND. Many thanks to you both – the cakes look delicious!

Trip to Tyntesfield anyone?

Maria (BBWW Group) is organising a trip to the National Trust's Tyntesfield (BS48 1NX) – the spectacular Victorian Gothic Revival house with gardens and parkland – for people living with MND and their carers/families. Fingers crossed it will be a lovely day, and we can wonder around the house and gardens, then visit the café. There is no set date yet, but we are looking at one weekend in June. Please note that there will be no Bath MNDa support group meeting in June, so we are hoping that many of you will join us on the Tyntesfield trip instead.

If you are interested, or would like any further information, please contact Maria on 07974783436 or maria@mnd-bbww.org.



<https://twitter.com/mndbbww>

Like us on Facebook



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

We are delighted that two keen, young bakers from Weston raised a fantastic £95.02 for the MNDa by selling their baked goods recently. The girls (pictured) are Amy Passarelli and Jenny Grieve from Worle in Weston Super Mare.

Forthcoming support meetings – Bath & Winsley

The 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.

6 May – Sally Light (Chief Executive of the MNDa) will be speaking

June – there will be no meeting in June – but see article on 'Trip to Tyntesfield'

1 July – Carolyn Read – Occupational therapist from Sirona will be speaking

Contact: Ruth Noakes
01225 316538; 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, **2–4 pm**

The next dates are: 30 May, 27 June, 25 July 2015

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

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.

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

Roman Baths and Pump Rooms, Bath. This Black Tie occasion, to raise awareness and funds for the MNDA, consists of a champagne reception, a three-course dinner, raffle and live auction. The event will be held at the stunning Roman Baths situated in the heart of this beautiful city. Guests will include local companies, private individuals and a few special guests!

To secure your ticket (£60 per person – tables of 10 or 12), or if you have any queries, please contact Emma Frampton, event organiser, 07841506412 or emmaframpton21@gmail.com. Payment by cheque or cash (cheques to be made payable to The Motor Neurone Disease Association).

Events diary

Saturday 16 May, 7.30 pm – Concert by The Weston Light Orchestra at Victoria Methodist Church, Weston – Tickets £6 (pay on the night) and all proceeds to the MNDA. Contact Ray for further information (0117 9755492; ray@mnd-bbww.org).

Friday 29 May, 7.00 pm – 'A World Free of MND' Black Tie evening event at The



mnda
motor neurone disease

Jump Fest 2015

Sky Dive to raise awareness & donations for Motor Neurone Disease

21st June 2015



Every donation makes a difference to a person living with MND

Choose your drop zone & register now for:

Cockerham - Lancashire, Hibaldstow - Lincolnshire, Beccles - Suffolk,
Sibson - Cambridgeshire, Swindon - Wiltshire, Dunkeswell - Devon,
Perranporth - Cornwall

<http://bit.ly/1vFBmZ> 01502 476131

Other Zones to be contacted directly:

Headcorn - Kent www.headcorn.com 01622 891670
Swansea - Wales www.skydiveswansea.co.uk 01792 207035

Or contact Pamela Fry 01202 849151 pamelafry@mndassociation.org
@pamelafrymnd

Motor Neurone Disease Association
102 Bala 246
Northampton NN1 2PH
Tel: 01202 595200
www.mndassociation.org



Thank you
for your
support

Registered Charity No. 26366

Saturday 20 June – MNDA Summer Festival – Eden Grove Methodist Church, Filton, Bristol Join us on this midsummer weekend afternoon for a celebratory event, with lots of fun for all the family. Come and listen to some live music, eat some cake, visit the lovely gardens and soak up the sun, all in aid of MND. Further details to follow shortly.

Thank you!

Back in November, Richard and friends from Santa Cruz Classic Cars held a festival in Keynsham and very kindly nominated the MNDA as one of their charities to support. We were delighted to receive a cheque from Rich recently for £2,000 – the proceeds from

the event. A huge thank you from us all at the BBWW MNDa for helping to raise our profile and for supporting local people with MND.

We would like to thank all of you who have recently raised funds for us, whether by jumping out of a plane, baking cakes or through memorial funds. All the money we receive goes towards supporting people living with MND, their families and carers, in the Bristol and Bath area.

June is MND Awareness month – national MNDa news



We are excited to share with you our brand new fundraiser for Awareness Month – Silence Speaks – where those who take part will be encouraged to find other ways to communicate throughout their sponsored silence challenge.

As you know, one of the things people with MND worry about is losing their voice, that's why 'losing your voice' is at the heart of our new fundraising activity.

A huge thank you to those of you who have signed our MND Charter and supported us over the last three years by promoting it and gathering signatures. We now have 29,000 signatures. Our target is to reach 30,000 by midnight on 6 May.



Please help us by sharing this link www.mndassociation.org/charter with everyone you know. The signatures will be presented to No. 10 Downing Street during Awareness Month.

Spotlight on research

Research published in *Nature Neuroscience* has identified mutations in the TBK1 gene as a cause of both inherited MND and frontotemporal dementia. The study was carried out in Germany and Sweden, and the next step is to develop models to study TBK1 in detail and find out if the mutation is also present in other populations including the UK.

Find out more about this, and other, research on the MND blog, <https://mndresearch.wordpress.com/2015/03/25/the-tbk1-jigsaw-puzzle>.

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: Andrew Grundy andrew@mnd-bbww.org
Regional Care Development Advisor (Bristol & West): Neil Drinkwater Email: neil.drinkwater@mndassociation.org
Secretary: Jon Wellington jon@mnd-bbww.org Tel: 07887 387724
Volunteering Development Coordinator (South West): Angela Lea Tel: 08453 751834/07887870473; email: angela.lea@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
Event Coordinator: Maria Baker maria@mnd-bbww.org
Newsletter Editor: Becca Ramsden becca@mnd-bbww.org
Digital Media Officer: Gareth Weaver gareth@mnd-bbww.org
Bristol & Weston Support Group Coordinator: Ray Hulbert MBE 21 Eden Grove, Bristol, BS7 0PQ. Tel: 0117 9755492; email: ray@mnd-bbww.org
MND Care Coordinator: Helen Madden 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: Helen.Madden@nbt.nhs.uk
Winsley & Bath Support Group Organiser: Ruth Noakes Tel: 01225 316538; email: ruth.noakes@homecall.co.uk
Association Visitor Helpline (BBWW Group): Heather Watson 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 becca@mnd-bbww.org 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.