

Note from the Chair



I'm sat here in my study sweltering in the heat; I have to admit I've been putting off any work on the computer waiting for the temperature to fall. But let's face it we shouldn't complain – it's about time we had a really good summer.

As always the team has been putting in quite some effort on the fundraising scene and you'll find articles about most of our activities in this newsletter. But without stealing their thunder I just have to mention our success in securing significant funding to help with the support group meetings, and the heroic effort of Gareth (our Digital Media Officer) who ran 100 miles in 29 hours (!!!) to raise awareness of MND and funds through sponsorship.

And finally a quick note about the film "I Am Breathing" – if you haven't had the opportunity to view it yet please do – we can help you get hold of a copy.

Andrew Grundy

BBWW group wins £4.5k lottery grant!

We are delighted to bring you the good news that we have been awarded £4,500 of lottery money to go towards funding our support group days. The grant comes from the Big Lottery Fund which gives out millions of pounds from the National Lottery to community groups and projects that improve health, education and the environment.



A huge thank you goes to Agnes, Andrew and Heidi for all their hard work and time spent filling out multiple application forms and jumping

through all the hoops required to secure the funding.

We are currently reviewing the format of our support groups and will soon be asking for your thoughts on this: a brief survey will be available shortly online and in print and we would encourage you all to fill it out so we can decide how best to support you.

Note from the Editor

Hello my name is Becca Ramsden and I've taken over from Elane as editor of this newsletter. Firstly, a big thank you to Elane for all her hard work in putting together the newsletter over the last few editions; I only hope I can keep her high standards going! I would really like to hear your thoughts about the content of the newsletter so please email me (becca@mnd-bbww.org) if you have any ideas. We would also like to know about any fundraising events you are taking part in so we can publicise them here as well as via our Twitter and Facebook feeds. Finally, if you are feeling creative and would like to write a letter or poem about MND to be included in the newsletter, I would very much like to hear from you!

Coming up in this issue..

- 100 mile non-stop run for MND
- Trip to Thornbury castle
- Embracing the digital world
- Day at the races
- The Banjo Festival
- How you can get involved
- Million cupcakes for grandpa

..and lots more!

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100 mile non-stop run for MND: beaten but not defeated!

Months and months of preparation had led me to this day. It was Friday 28 June and I was heading up to Stratford-upon-Avon to compete in my toughest ever challenge - the Cotswolds Ultra – a 100 mile non-stop run around the hills. Weaving in and out of the undulations we finally arrived at the most modest of start places - Stratford Leisure Centre car park. If I wasn't feeling nervous before, I was now. As tall, gangly, gazelle-like men bounced across the tarmac to register inside, I thought to myself 'Oh Gaz, what have I done?!'



Looking fresh and ready to go at the start

Forty runners set off at midday. The conditions were warm and humid. I ran with my friend and club mate Marc who was also running in memory of his father. It was a gentle pace out towards the hills. There were checkpoints every 10 miles where the marshals could keep track of us and runners could refuel and repair! The menu, for me, consisted of pizza, bagels, nuts, fruit and cake which I would eat on my breaks or on the run. At every stop I was greeted by my wife and a growing entourage of supporters who provided much needed banter.

At 20 miles, Marc and I split and he ran on ahead. I had a team of support runners who I had persuaded to keep me company as I made my way through and over the beautiful landscapes of the Cotswolds. Time went quickly and I kept up a steady pace reaching halfway in 10 hours! 50 miles was the furthest I had ever run and from now on all was new. The night set in and bearing a head torch I trudged into the darkness. I began to feel tired and nauseous. Not being able to eat was a worry and my legs tightened. When I reached 60 miles I knew it was going to be a struggle and my ambition of finishing in less than 24 hours slowly slipped away.



Me alongside my running partner Marc

By the next 10 miles I was walking and collapsed into a camping chair at the next checkpoint. It was 5am and I had been on the move for 17 hours non-stop. My feet were covered in blisters and I was still feeling sick. My focus changed all I had to do now was finish! The following 30 miles were very slow, hot and painful. I kept going in the knowledge that what I was going through was nothing compared to what people affected by motor neurone disease go through. I was never going to give up!



It's all over – phew!

After 29 hours 11 minutes and 6 seconds I completed 100 miles of hilly road to my cheery, fantastic supporters. What a day and a half?!

Thank you to all my sponsors who kindly donated. The latest total raised on my website <http://gazruns100.com/> reads at **£4095.10**. Thank you! I also managed to get into the Bristol Evening Post a few times as well as other local press, spreading awareness about MND and our support group. Job done!

So...what's next?!

Gareth

**An easy way to sponsor Gareth:
text 'GAZW99' and '£10' to 70070**

Trip to Thornbury Castle

In June the Bristol and Weston group enjoyed a sunny afternoon at Thornbury Castle organised by Dianne Hunter. We were given an excellent tour and talk on the history of the castle and its grounds by Valarie Quine of the castle. The sun shone (as I expect it did for Henry VIII and Anne Boleyn during their stay at the castle!) and we enjoyed tea in the



impressive Baron's sitting room which is wood-panelled with a beautiful imposing original fireplace. A lovely cake was donated by Vicky Edwards (www.victorias-cakes.co.uk) for Gareth's impressive 100 mile run around the Cotswolds to raise money for MND.

Gemma Storr



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
1.30-3.30pm

6 September
4 October
1 November
6 December

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

August – no meeting
28 September: 'Gareth –
My 100 mile run in aid of
MND'
26 October: speaker TBC
30 November: Patrick
O'Neill – specialist in wills
and powers of attorney
14 December: Christmas
party at Eden Grove

Contact: Ray Hulbert
0117 9755492
ray.hulbert@yahoo.co.uk

Embracing the digital world

In the spring newsletter we introduced our brand new local website (www.mnd-bbww.org) expertly created by the multi-talented Gareth Weaver. Please get in touch and let us know what you think of the website and any suggestions for improvements by emailing Gareth at gareth@mnd-bbww.org. We are also on Facebook and Twitter where we post snippets of news and upcoming events. If you



would like to join our online community, you can 'like' our Facebook page at: <https://www.facebook.com/mndassociation.bbww> and 'follow' us on Twitter at: <https://twitter.com/mndbbww>.

If you would like to receive an electronic rather than paper copy of this newsletter, please let me know at: becca@mnd-bbww.org.

Anyone for **LINE DANCING**? Come along to a special event being held at Eden Grove Church, Bristol (BS7 0PZ) on **Friday 20 September at 7pm** - for an evening of fun to raise money for MND – and don't forget your dancing shoes!

Day at the races

We were very pleased to be invited to Bath Racecourse by Jess Lloyd on 11 July to raise funds for MND. Three cheery volunteers attended with collection buckets. We were very lucky as the weather was sunny and warm and so we had a lovely day out as well as raising awareness and funds for our group. We would like to thank the staff and patrons of Bath Racecourse for their generosity as we raised **£347.14**.

The Banjo Festival

A two day banjo festival was held in Marshfield on 14th and 15th June; the first evening was an informal affair in a local pub where various local talent played their stuff. The second evening was held in the local community centre and included two star acts, Dan Walsh and Leon Hunt, who were truly fabulous (and I'm not a banjo fan, but if you are familiar with 'You Tube' then I can recommend a listen).

The takings from the festival (**£412**) were shared between the Pappa Fund and MNDa. The performances were dedicated to the memory of Alistair Banks and it was nice to see Alistair's family there. The organiser Matthew was one of Alistair's music buddies and he appears on the "Alistair the Optimist" CD.



Would you like to get involved?

Do you like the sound of spending the day at the races or an evening in a pub? We are looking to recruit a bank of volunteers who we can call on to shake a bucket and help out at various events across the region. You would only need to spare a morning or afternoon every couple

of months and we guarantee you will have fun at the same time! If you can spare the time and would like to help us raising awareness of MND and the profile of our local group, please contact Agnes Williamson at: agnes@mnd-bbww.org.

Bleadon Sugarcraft Show

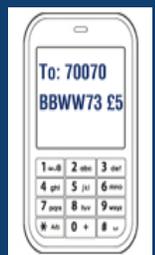
We are thrilled that the organisers of the annual Bleadon Sugarcraft Show have chosen the MNDa as their charity for 2013.



The show will be held at Winter Gardens in Weston-super-Mare on **Saturday 7 December** from 10-15.30 and we will have a table there. There will be sugarcraft equipment and cake-top decorations for sale and demonstrations throughout the day.

Watch this space for further details!

You can DONATE money to our group through your mobile phone. Simply text 'BBWW73 £5' to 70070.



Or visit our JustGiving page:

<http://www.justgiving.com/MND-BBWW>

Help to set the MND Association's priorities for the next three years

The Motor Neurone Disease Association (MND) needs your help to set our priorities for the next three years. Our mission is to fund and promote research, campaign and raise awareness about MND towards our ultimate vision of a world free of MND. We are now inviting anyone with a link to MND (whether you are living with MND, a carer, volunteer for the Association or have any other connection to MND or the MND Association) to fill out a brief survey to help us decide how best we undertake our mission from 2013 to 2016. The survey can be accessed at:

<http://www.mndassociation.org/about-us/Out+Future> and the deadline for completing it is **21 August 2013** (it only takes 5-10mins). We would really appreciate you filling out the survey and welcome your views.

Million cupcakes for Grandpa

Two children from North London are aiming to raise a million pounds for the MND Association by opening their very own virtual cupcake shop. Ella, 10, and Oliver, 7, have created 'Million Cupcakes for Grandpa' in memory of their grandfather Michael, who died from motor neurone disease in December 2012, aged 66.

'Million Cupcakes' allows you to buy one of four delicious virtual cakes and send it, along with a personalised message, as a present to someone special. To find out more and send a cupcake, visit

<http://www.millioncupcakes.org/>



I Am Breathing is an awareness-raising film about a young dad with MND. The film was launched on Global Awareness Day (21 June) and has been screened around

the world. It's not too late to hold your own screening – visit www.iambreathing.com for further details.

Attention cyclists! If you know anyone who is a keen rider please encourage them to join Beccy on **Bec's Big Bike Ride**

around the UK coastline. Visit her website – <http://www.becsbigbikeride.com/> - to find out more about this epic challenge.



Tissue donation: leave a lasting legacy for MND research

Find out more about how you can donate brain and spinal cord tissue for use in MND research after your death at:

<http://www.mndassociation.org/news-and-events/Features/Tissue+Donation>

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: Andrew Grundy akgandajg@live.com
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@chartax.biz
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: hadm@hd990605.wanadoo.co.uk
Fundraising: Agnes Williamson agnes@mnd-bbww.org
Publicity Officer: Jon Wellington jon.d.wellington@gmail.com
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.hulbert@yahoo.co.uk
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>

Further information can be found on the national web site at www.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.

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.