

A Note from Our Group Chair, Andrew Grundy



Welcome to the spring addition of our Newsletter - let's hope that the recent good weather is a sign of a good summer to come.

You'll see that our supporters in the BBWW area continue to be very active in all sorts of ways. Of course, there are the regular support group meetings, and the forthcoming visit to Thornbury castle, and the ongoing fund raising activities with the MND Awareness month of June soon upon us. But in addition you'll see our determined push into the

digital world with the launch of our website, and links into social media sites such as Facebook and Twitter. Please take a look and let us have your feedback.

I also have great pleasure in welcoming Agnes Williamson onto our team as Fund Raising Coordinator. She is eager to hear from all those with good ideas and keen to help with fund raising (contact details on back page).

If you have any items you would like us to include in our next newsletter, or if you would like to find out more about how we can help you, please contact one of our team (details on the back) or visit our webpage <http://mnd-bbww.org>.

Sign The MND Charter

On 1 June 2013 the launch of the MNDA Charter will be celebrating its first anniversary. The Charter is asking **EVERYONE** to sign up and ask the government to show us what **good care** looks like for people living with MND, and for their carers. **Anyone can sign up to the MND Charter**, and by doing so you are showing that you have listened to the voice of people with MND, and their carers, and pledge to understand and support the principles and priorities set out in the Charter. It takes **just 2 minutes** to sign online. Visit this link to sign up:

<http://www.mndassociation.org/NR/exeres/81C300FD-BCE4-491C-B691-2F6361A12390>

The MND Charter has 5 Aims to help people with MND have the right to:-

1. an early diagnosis and information
2. access quality care and treatments
3. be treated as individuals and with dignity and respect
4. maximise their quality of life
5. have their carers be respected, valued, listened to and well-supported.



**The Motor Neurone
Disease Association
Charter**

SPRING 2013

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If you'd like to contribute something for the newsletter please email Becca at becca@mnd-bbww.org



Sign up to or download the MND Charter at www.mndassociation.org

Our New Look Website!

In February 2013, the Bristol, Bath, Weston and Winsley Group launched a brand new website. Gareth Weaver, who created the website, said "I hope it helps spread awareness of the Association and promote the good work of the Support Group in the local area, and of course internationally! There has been a good reaction so far to the site and I hope to develop it further in the future."

The website has information on MND, support services and some useful contacts and links. The pages host all the latest news from the Group and Association as well as all the events that BBWW are involved in.



What our website looks like!

So come and visit us at: <http://mnd-bbww.org>

As well as the website the group has a presence on Facebook, Twitter and JustGiving. If you use any of these then please...

FACEBOOK

Like us on Facebook



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

TWITTER

Follow us on Twitter



<https://twitter.com/mndbbww>

JUSTGIVING

Donate at JustGiving



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

All of these links are displayed on the website too and if you're not already on Facebook or Twitter you can sign up through our weblinks - why not give it a try?

We would LOVE to hear what you think of our new website and all our new communication streams. So please email gareth@mnd-bbww.org if you have any comments or would like to know more.

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



MND Centre at Frenchay Hospital

The MND Centre at Frenchay Hospital is operating well since its opening last year. If you feel you need extra support as a person living with MND or as a carer please get in touch with our main contact for the centre:-

Hilary Fairfield, Regional Care Development Adviser, MND Association, **0845 375 1828** or via email hilary.fairfield@mndassociation.org

OR

Contact the Centre directly on **0117 340 2287**.

Dying Matters Awareness Week – 13-19 May 2013

Several different writers have been attributed with saying “there is nothing as certain as death and taxes.” As we know, both are inescapable!

Whilst various companies have been in the press recently for trying to avoid taxes, it isn't quite as easy to avoid death – for any of us.

The Dying Matters coalition aims to positively change attitudes and behaviour amongst the whole population around talking about and planning for this eventuality.

Each year there is an awareness week with a different theme. In 2013, awareness week is being held from 13 – 19 May and the theme is 'Be ready for it'.

Here are five crucial actions you, your friends and family can take during and after Awareness Week:-

5 Crucial Actions to Positively Change Attitudes Towards Death

1. Make a will
2. Record your funeral wishes
3. Plan your future care and support
4. Register as an organ donor
5. Tell your loved ones about your wishes



Tweeting for Awareness

A new initiative is being launched for Dying Matters Awareness week. The Dying Matters coalition would like to hear what people might tweet about if they were to communicate one last time in writing. They are not asking people to actually tweet, but to submit examples to them and Dying Matters will publish the best in an anthology.

Support Group Days

Each month there are two support groups you can attend within the Bristol, Bath, Weston and Winsley area. The details for these groups are:-

Bath & Winsley area
1st Friday of every month

Winsley Church Hall,
BA15 2LH
1.30pm-3.30pm

Contact Daphne Cox
☎ 01225 868224
daphne@daffers.org.uk

Bristol & Weston area
Contact Ray Hulbert
☎ 0117 9755492
@ray.hulbert@yahoo.co.uk

Saturday 2 June
2pm-4pm
Milton Methodist Church
Weston-Super-Mare
BS22 9RA

Wednesday 26 June
Thornbury Castle
(see page 8 for details)

Saturday 27 July
BBQ and Cream Tea!
2pm-4pm
Eden Grove Methodist
Church, Filton, Bristol

If you would like to find out more, please contact The Dying Matters team via email



info@dyingmatters.org or
freephone 08000 21 44 66

June is MND Awareness Month!

This year we have expanded our traditional MND Awareness Week to cover the whole month of June to create our first ever MND Awareness Month!

We are asking for you to help us raise essential funds needed to maintain our care services and research programme. You can help us by holding a fundraising event during MND Awareness Month in which we are aiming to raise £250,000 to use where it is most urgently needed.



There is a whole host of ways in which you can raise funds for us. How about organising a pub quiz or cake sale or even a charity ball or auction? Or you could ask for sponsorship for doing something crazy like shaving your head! If you would like to help but are stuck for an idea, why not browse some fundraising ideas on the national website www.mndassociation.org.

We want to help you in your quest to raise valuable funds for MND. Please email us for a fundraising pack (fundraising@mndassociation.org) or call us on 01604 611860 for some brainstorming!

June Is MND Awareness Month - Bake It



It's time to roll up your sleeves, put on an apron and get baking! Our 'Bake it! - Fundraising Pack' is full of ideas, tips and fundraising materials to help you organise the perfect baking event to raise funds for MND. Join the baking craze sweeping the nation and show your support during MND Awareness Month in June.

Start by choosing a venue and a date/time, invite your guests and don't forget to spread the word by advertising your baking event well in advance.

Why not ask your friends and family to get baking too as the more you bake, the more funds you will raise!

bakeit!

If you're unable to hold an event but would still like to support the work of the MND Association please text CAKE00 £5' to 70070.

Your help really
DOES make a BIG
difference

June is MND Awareness Month! – I Am Breathing

If you would like to help Neil's vision come true and raise awareness of MND by arranging a screening of 'I Am Breathing' in your area, please email emma.johns@mndassociation.org.

MND Awareness Month this year is focused around a film called 'I Am Breathing'. The film tells the story of Neil Platt, a father who found out he was dying from MND just months after the birth of his son Oscar.

Neil wanted to raise awareness of MND as well as leaving a memory box for his son. He invited cameras into his house in Yorkshire so that his last few months were captured forever.

The moving documentary will be screened on MND Global Awareness Day on 21 June 2013. A clip from the film can be viewed at <http://www.iambreathingfilm.com/>.



June is MND Awareness Month - Raffle 2013

Every £1 ticket sold offers the chance of winning over 50 great prizes, worth over £7,000, while raising much-needed funds for our vital work.

Last year our supporters' fantastic efforts helped make our annual raffle a great success, raising nearly £134,000 to help fund our essential care support services and research programme.

The raffle closing date

is 21 June 2013

If you would like raffle tickets, please call 0845 6016936 or email raffle@mndassociation.org or visit

<http://www.mndassociation.org/getinvolved/fundraising/Raffle+2013>



Raffle Prizes are:-

1st prize: **£4,000 cash**

2nd prize: **£500 cash**

3rd prize: **£200 cash**

50 runner up prizes
kindly donated by Next Retail

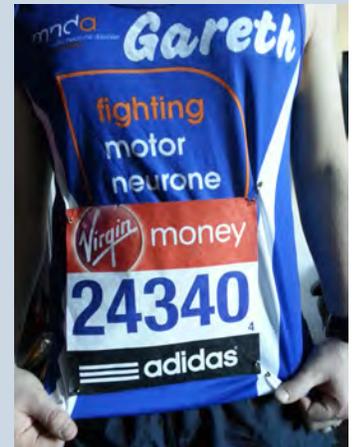
June is MND Awareness Month! - Walking for MND

Gareth

Fresh from his triumph running the London Marathon in April, our Group's very own Gareth Weaver is planning to run 100 miles non-stop, yes, you read it correctly, 100 miles, to raise awareness and LOTS of money for our charity. In true Proclaimers' style singing "I Will Run 100 Miles" Gareth's trek starts in the hilly Cotswolds on 28 June and he runs through the night to Stratford-upon-Avon, finishing 24 hours later. Yes, Gareth will be running without any sleep! We all think he's mad, but we're very proud of him and we hope you are generous with your donations.



Our BBWW Group's Gareth strutting past Big Ben in the 2013 London Marathon



How To Sponsor Gareth

Visit gazruns100.com OR go directly to :-
<http://uk.virginmoneygiving.com/gazruns100>
<https://www.justgiving.com/gazruns100/>
 Text 'GAZW99' and '£10' to 70070 OR
 Email geeweaver@gmail.com

Laura

Another of our Committee members, Agnes, is proud to announce that her daughter **Laura Williamson is walking/jogging 100k from London to Brighton** on 25 May (in one day!) to raise money for MND.

You can sponsor Laura at
<http://www.bmycharity.com/Laura100km>

If anyone would like to make a donation they can go to www.bmycharity.com and then type in **Laura Williamson** in the 'Find a Friend' box to bring up her sponsorship page, as shown below.



Home | Charities | Fundraisers | Donors | About us | Contact | Help

FUNDRAISER: LAURA WILLIAMSON

My page: <http://www.bmycharity.com/Laura100km>

MAKE A DONATION

Please enter the amount you would like to donate

£

RUNNING TOTAL

£0 £140.00 £350.00 £560.00 £700.00

£350.00 **£65.00**

Raised so far Gift Aid¹

Total Raised online: £350.00

Total Raised offline: £0.00

Fundraising target: £700.00

MOST RECENT DONATIONS

Name	Amount	Gift Aid
Natalie Anderso...	£10.00	£2.50
Geoff Baker	£15.00	£0.00
Lyn Crookin	£20.00	£5.00



Hello and Welcome from Laura Williamson 100km London2Brighton Challenge

Hello,

I have crazily signed up to do a 100km walk/jog from London to Brighton in one day!

The last time I did a charity event my dad ran the half marathon with me, however this time I am doing it on my own to raise money for the MND Association. It is a charity that has been wonderful to my family over the past couple of years since my dad was diagnosed with Motor Neurone Disease in March 2011. Over the last two years his mobility, in particular, in his legs has deteriorated and he is now in a wheelchair.

So on 25th May 2013 I will be setting off from Richmond Upon Thames. The route heads south into the suburbs of London, then on through the heart of Surrey and Sussex, over the South Downs towards the finish line in Brighton.

Fundraising Through Music



A photo taken from the 20k route
(Source: The Rotary Club website)

Fancy a stroll? Why not join hundreds of fellow ramblers on 23 June 2013 for a walk through the picturesque countryside surrounding Nailsea and raise money for MND in the process?

Now in its second year, the annual Nailsea Charity Walks offer the opportunity for walkers of all abilities to raise money for a host of charities, one of which is MNDA. There are three distances on offer depending on your preference: Nailsea Stroll - 5k, Nailsea Walk -10k, or Nailsea Challenge -20k. The walks are also open to runners for the first time this year.

There is a £5 entry fee per walker and all walks start at The Scotch Horn Centre, Brockway, Bristol, Avon BS48 1BZ.

The walks are organised by The Rotary Club of Nailsea & Backwell. Full details can be found at <http://www.nailseaandbackwell.rotaryweb.org> or by contacting Graham Hunt, 07970 771845 – grahamjeanhunt@tiscali.co.uk.

Jumping for MND!

If you fancy JUMPING for MND why not take our Skydive challenge? The date set is 17 July and you need a minimum of £395 sponsorship for a free jump. Log onto www.skydiveukltd.com/?x=view-charity-profile&profile=112 for details.



June is MND Awareness Month! -

An Afternoon At The Castle

You are all cordially invited to Tea and a Tour at Thornbury Castle on **Wednesday 26 June at 2pm until 4pm**. Following last year's 'Tockington Day Out', Dianne Hunter, one of our Association Visitors, has organised an afternoon tea and tour for anyone connected with our MND Group. The Castle, probably one of BBWW's most luxurious venues. boasts a beautiful Tudor hall, walled gardens and a 500 year old vineyard where the Muller Thurgau grape is grown and harvested.

If you want to book your place or you would like more information please contact **Dianne** on **01454 613990**. There is disabled access and tea and biscuits will be provided!



Thornbury Castle has hosted Kings and Queens and its doors are open to all of us too in June

Fundraising Through Music

If you have an event or concert which you think would be appropriate to choose MND as your chosen charity for donations / collections, please contact our Chairperson, Andrew Grundy, via email akgandajg@live.com. The more money and awareness we can raise, the more hope we have for a future living without Motor Neurone Disease. Thank you.



Thank you to Vanessa Pinniger, who invited us to a concert in St George, Bristol on Saturday 2 March.

The orchestra treated us to Dvorak's Symphony No 9, Gershwin - Piano Concerto (with Ashley Wass as pianist), and Bernstein's Candide Overture. The conductor was Stefan Hofkes.

It was a retiring collection amounting to over £600 which has gone to the Tribute Fund for David Roberts. Thank you to all who donated to the cause.

▫ The Bristol Male Voice Choir

We were very pleased to be presented with a cheque for £300 recently from the Bristol Male Voice Choir. Members of the choir decided to donate money to a good cause instead of sending each other Christmas cards last year, and we are delighted that they choose MND. Thank you!

Their generous donation was presented at a recent event and will be used for local funds.

The choir has been running for 45 years and is one of the largest male voice choirs in the west country. To find out more, visit their website at <http://www.bristolmvc.org.uk>

Volunteering - We'd Love You To Join Us!

We are always looking for volunteers to help out at charity events so if you have some spare time on your hands and would like to make a difference to people with MND we would LOVE to hear from you.

We are always pleased to hear from people who would like to become an Association Visitor. This requires training and is a valuable part of assisting people living with MND. We are particularly keen to hear from people who live in Bath and South East Bristol as we have a number of people in those areas living with MND and not enough support to visit those people in their homes.

To find out more about how you can help at events, please contact **Andrew Grundy**, our Group Chairman. His contact details are on the back page.



To find out more about how you can become an Association Visitor, please contact **Hilary Fairfield**. Her contact details are on the back page.

Alistair Banks – The Incurable Optimist

After a remarkable effort at raising awareness of people living with MND it is with sadness that we write our obituary for Alistair Banks, who passed away on 9 January. Alistair had become our national ambassador for MND under the name 'Alistair the Optimist' and was one of our very own, regularly attending Daphne's Support Group in Winsley. Alistair appeared on television, radio, poster campaigns on the London underground, made a documentary, recorded an original CD with his band and even carried the Olympic Torch! His Facebook page was updated by his family who said:- "Alistair went peacefully with his family beside him, with the dignity he deserved after enduring this wicked disease. We are so very proud of the way that despite the disease he has inspired so many people and left such an incredible legacy for his children and others. As a family we will continue to raise awareness of MND and hope you will join us."

The BBWW Group would like to thank the Banks and de Lap families for all their efforts in raising awareness about MND. Alistair's legacy does indeed live on.



Alistair's CDs are still available for sale – Visit <http://alistairtheoptimist.org> to purchase a CD or make a donation

Marcelin Fortes da Cruz

It is with sadness that we write that 61 year old Marcelin Fortes da Cruz passed away peacefully on Sunday 10 February after a long battle against Motor Neurone Disease. There was a large attendance at his cremation held at the Westerleigh Crematory on Wednesday 20 February.

Born in Dakar, Senegal, he also has connections with Cape Verde Island and Portugal before moving to France at the age of 17 where he studied at Lyons University as a Mechanical Engineer. He joined Airbus about 28 years ago as a System Engineer and moved to the Bristol branch in the last decade where he worked until his death.

Marcelin started having symptoms of MND in 1996 but was only diagnosed with the disease in 2002. He was a great fighter and an optimist as he used to declare that he would never let the disease conquer him. This is epitomised in the song 'Never Give up' which he sang accompanied by Janet Lings during his Music Therapy sessions at Bristol Oncology Centre. The recorded song was played at his Cremation. He believed very firmly in the therapeutic benefits of Music Therapy and his wish is that this is made available to more MND sufferers. He was also the champion of many causes to help and support people living with MND and supported our local BBWW Group, even taking the task of Chairman for one year.

He was a good musician and was quite proficient playing the guitar, saxophone and clarinet. He also played the xylophone during his music therapy classes. He was a good sportsman and very proficient at Judo having won his Black Belt when he was quite young. He taught Judo to children in Senegal, France and even Bristol at the beginning of his stay in our city. He was a very determined person and above all he was very intelligent. He did not let MND prevent him from studying for a PhD at Bristol University. He was, in fact, in the process of writing his thesis when his untimely death arrived.

Marcelin leaves behind two daughters and two sons and Tessa Northcot his beloved partner of 8 years. Tess and Marcelin met at the Sailing Club for people with Physical Disabilities and were together ever since then. Tess was very devoted and cared for him with compassion and love until his last breath. We will all miss him.

Thank You To Our Volunteers!



Special awards were recently presented recently at the Bristol & Weston Support Meeting to our longest serving volunteers. Former Filton Golf Club Captain and MND Fundraiser Roy Oaten presented three Star long service awards to the volunteers who were praised for their longstanding commitment to the Association and sincerely thanked for all their time and effort which has made a real difference to people with MND. Pictured from top left is Roy with:- Gillian Joomun, Rashid Joomun, and Anne House (who received a 10 year service award). From bottom left:- Les Rowe (who received a 5 year service award), Ray Hulbert, (who also received a 5 year service award) and Gill Osman.

Contacts

Chair Andrew Grundy @ akgandajg@live.com	Regional Care Development Advisor Hilary Fairfield ☎ 01373 826289 @ hilary.fairfield@mndassociation.org
Secretary Sue Paulley 45 Charlton Road, Keynsham, NE Somerset, BS31 2JG ☎ 0117 9376050 / 0117 7987233 @ sue@chartax-bristol.co.uk	Volunteering Development Co-Ordinator (South West) Lucy Etheridge ☎ 0845 3731839 / 07831 098365 @ lucy.etheridge@mndassociation.org
Treasurer Heidi Frydman 4 Brayne Court, Longwell Green, Bristol, BS30 7DS @ hadm@hd990605.wanadoo.co.uk	Fund Raising Coordinator Agnes Williamson @ agnes@mnd-bbww.org ☎ 07984 783345
Newsletter Co-ordinator Becca Ramsden @ becca@mnd-bbww.org	Bristol and Weston Support Meeting Co-Ordinator Ray Hulbert MBE 21 Eden Grove, Bristol, BS7 0PQ ☎ 0117 9755492 @ ray.hulbert@yahoo.co.uk
Digital Media Officer Gareth Weaver @ geeweaver@gmail.com	
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 ☎ 01225 868224 @ daphne@daffers.org.uk
Association Visitor BBWW Group Helpline ☎ 07516 023675	

If you would like to talk with someone about MND 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.bristol.co.uk 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.