

## Bristol & Bath Group Newsletter – Autumn 2015 [www.mnd-bbww.org](http://www.mnd-bbww.org)

### All change (well 50%) on the committee!

'It never rains but it pours' is the saying that springs to mind when I look at the recent changes in the Bristol & Bath MND Group Committee. It is to be expected that there will occasionally be changes on the committee, and indeed it is a good thing now and again to bring in new ideas and ways of doing things. But in our case, circumstances have conspired such that, in a relatively short space of time, there has been a significant change of committee members – four to be precise – all for different personal reasons. I just wanted to mention their names and say a few words of thanks for all their efforts over the years.

Firstly, **Ray Hulbert**. For those of you who know Ray, and I would guess that that is a lot of you, you will know what a staunch long-term supporter and volunteer Ray has been. Simply the amount he has done and the energy levels he



brings to everything he does has been inspirational and a massive help to the organisation. On a personal note, I took over the role of chair in 2011, the last time there was a significant change of the committee, and it was Ray as a long-term member of the committee who helped me through the initial stages of rebuilding the committee, and keeping MND activities running. With Ray's vast experience he was the foundation upon

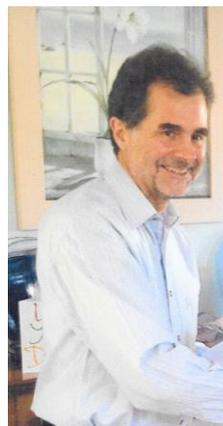
# MNDa bristol & bath

Supporting local people affected by  
Motor Neurone Disease (MND)

which we rebuilt the group. Thank you Ray – enjoy taking it a bit easier.

Secondly, **Heidi Frydman**. Heidi is probably less well known because much of the valuable work she has done as treasurer has been in the background. Heidi has helped keep us in financial health through ensuring that our books were in order and that all the information was readily at hand. In particular, her efforts in handling the paperwork relating to the grant we received from the Lottery was Herculean – she did a great job largely unseen – thanks Heidi.

Thirdly, **Agnes Williamson**. Agnes was our fundraising coordinator, and will be missed for her enthusiasm and her willingness to challenge ways of doing things when change was probably required. Thanks Agnes.



And who is the fourth? Me I'm afraid. It is with sadness, and much soul searching, that I leave the post of chair, but personal circumstances have led me to conclude that our local MND group will be best served by me standing down. I have thoroughly enjoyed working with everyone involved and will continue to volunteer from time to time. I wish the remaining members of the committee – Jon, Becca, Gareth and Maria – all the very best for the future in supporting people with MND.

Best wishes  
**Andrew Grundy**

Hilary Fairfield, MNDa Regional Delivery Manager, now writes a few words about some of the familiar faces we're bidding farewell to.

**Andrew Grundy** – When Andrew made the mistake of moving to Winsley, little did he know that he would soon be 'persuaded' by Daphne Cox (a long-standing Association Visitor in the area) to attend the MND support group that was then held every month in Winsley Church Hall. Before too long, he rashly agreed to join the Group committee and become the Group Leader for the Bristol and Bath group. Over the next couple of years he brought new volunteers on board and helped to give the committee more structure and focus. His contribution has been much appreciated.

**Ray Hulbert** – Anyone who has met Ray will know that he is a man of immense talent, numerous network contacts, good ideas and tremendous energy. He has given tremendous service to the MND Association and been the driving force behind the Summer Fair at Eden Grove, Bristol and the Bristol MND support group. His links with Eden Grove church have been incredibly useful, as the community centre there has been the base for a large number of meetings and events. Ray's contribution has been highly appreciated and we extend sincere thanks to him for all his energy and enthusiasm over a number of years.

**Dianne Hunter** – Dianne showed a strong interest in MND many years ago when she put herself forward as the 'link nurse' for MND from St Peter's hospice. Gradually this interest extended until the time she trained as an Association Visitor over four years ago. Since then, she has provided valuable support to fourteen individuals and families in the South

Gloucestershire area. Her contribution has been much valued.

### Vacancies on the committee

Following the departure of our friends, we are now recruiting for a number of positions. If you know anyone you think might be interested in some voluntary work, please do put them in touch. We're a friendly bunch (see photo!) and new faces are always very welcome. We are



currently seeking a: **Group Leader**, who is the focal point of the group's work in supporting people with MND, who should be aware of all the activities being undertaken by group volunteers, and who should bring a sense of continuity to group work;

**Finance Officer**, who should be reliable, have good numerical skills and the ability to keep records, bank donations and write thank you letters to donors;

**Support Group Coordinator** for the Bristol area whose role is to organise monthly gatherings for people living with MND and their families/carers; and

**Fundraiser**, who will organise collections at supermarkets, for example, and create other opportunities for fundraising in the local area. Further details can be found at <http://mnd-bbww.org/volunteering>.

We are also looking for **General Volunteers** to help us out at various events, so please do get in touch and register your interest with us. If you have any queries or to talk through any of the roles, please contact Jo Campbell (details on back page).

## Join us at Bath Christmas market

We are thrilled to have been allocated a stall at the Bath Christmas market this year. Plans are well underway for Sunday 6 December, when we'll take over the charity chalet for the day (10 am to 6 pm). It's a lovely spot by the abbey, and in the past, we've found this to be a very enjoyable and effective means of raising awareness of MND and raising much needed funds.



On the day we will be handing out of information about MND, our local group, and the national organisation; selling certain MND merchandise, mainly Christmas cards; and running our very popular tombola.

If you would like to help us, we would appreciate any donations of new or unused items for tombola prizes\*, and if you have time to spare and can help on the day, we have a roster covering one hour slots at the chalet throughout the day (please contact Andrew Grundy – [Andrew@mnd-bbww.org](mailto:Andrew@mnd-bbww.org)) and your help would be very much appreciated. Please share this information with friends and family members who might be interested too.

\*please contact Becca ([Becca@mnd-bbww.org](mailto:Becca@mnd-bbww.org)) or 07967273595 to arrange delivery/collection of your donation(s)

## Visiting a gothic masterpiece

Back in August, seven of us went to look around Tyntesfield House and Gardens. Tyntesfield is a Victorian country house

and estate, located just outside Bristol, where the Gibbs family previously resided. The family made a fortune from the trading of guano from South America, and transformed the house in a majestic gothic masterpiece.

Upon arrival, we caught the mini bus to the main house, where we were given a brief history by one of the National Trust volunteers. After this, we set about our self-guided tour throughout the 24 rooms. Throughout 2015, the National Trust have



been focusing on the second generation of the Gibbs family who lived in Tyntesfield, meaning that the focus was on Anthony Gibbs, and the changes he made to the house

Following our tour of the decedent ground floor, we proceeded to the upper level, and toured the numerous bedrooms and bathrooms, which included a Victorian power shower. Although half the first floor was closed for restoration, you could still appreciate what it must have been like to live there. Our loop finished off in the chapel, which was previously used by the Gibbs family and members of the estate.

After our visit to the house was complete, we headed to the cafe to finish off our day with a bit of tea and cake! Thank you to everyone who came along for a thoroughly enjoyable day out.

**Maria**

## 'Right Chair, Right Time, Right Now' – pledge your support

Jean Waters, Chair of the MND A Gloucestershire Branch, is a member of the Wheelchair Leadership Alliance, which formed in January 2015 under the leadership of one of the UK's best known Paralympic athletes, Baroness Tanni Grey-Thompson. This Alliance is a commitment group campaigning for a better deal for wheelchair users and aims to transform the quality and effectiveness of services across England.



A dual approach has been adopted to improve wheelchair service provision and therefore to improve people's lives as quickly as possible: the 'Right Chair, Right Time, Right Now' campaign, and the development of a 'Wheelchair Charter', which were both launched on 20 July 2015.

The Wheelchair Charter outlines ten principles by which wheelchair services should be commissioned and delivered to ensure that people get the Right Chair at the Right Time. We are asking service users, manufacturers, providers, voluntary sector organisations, commissioners, clinicians and members of the public to pledge your support for the charter principles and the need for those in power to commit to delivering against them. By pledging your support we will, together, be able to start the change, commit to better service delivery and an improved quality of life for every wheelchair user.

We urge you all to visit the links below and sign the charter. You can also write to your MP and Clinical

Commissioning Group to ask them to pledge their support for the charter.

[www.rightwheelchair.org.uk](http://www.rightwheelchair.org.uk)

*Article by Jean Waters, Chair Gloucestershire Branch MND A and Wheelchair Alliance member*

## Update from Bristol MND care centre

The care centre continues to be busy supporting people with MND and their families from across the region. We recently ran our first study day in September in Bristol, which proved to be very popular with nearly 100 health and social care professionals attending. We had various speakers covering topics such as diagnosis of MND, role of therapies (Physiotherapy, Occupational Therapy, Speech & Language therapy & Dietetics), respiratory surveillance including non-invasive ventilation and cough assist, the role of MND Association and palliative care. Feedback received from the study day was very positive and we plan to run further study days in the future to support health and social care professionals in their work caring for people with MND and their families. We were also grateful for four Association Visitors who kindly volunteered their time to help with the running of the day; they also had the opportunity to speak to delegates about the work of MND Association alongside Neil Drinkwater during the breaks. In other news we plan in the next few months to send a questionnaire to people with MND known to the care centre for their feedback on our service, as we continue to strive to improve the service we provide.

**Helen Madden**



## An invitation from Bath support group

While the Bristol & Weston support group is having a temporary break, Ruth Noakes, who organises regular meetings in Bath, would like to invite all plwMND and their carers in the Bristol, South Glos and Weston-Super-Mare areas to join with the Bath group.

There will be no group meetings in December or January (due to Ruth being out of the country) but in the new year, the group will resume with a meeting at Foxhill Community Centre Hawthorn Grove (off Entry Hill) Bath BA2 5QD on Wednesday 3 February 2016 at 2.00 pm. The hall is open from 1.30 pm and we usually run till 3.30 pm. There is plenty of parking.

If you would like to come and require transport please arrange a taxi and tell the driver that Ruth will pay on your arrival. Please let Ruth know by email if you do intend to come so she can look out for you. Lots of information is available as well as Association Visitors being on hand to answer any questions. We hope some of you can come along.

**Ruth Noakes, Support Group Coordinator;**  
**(01225 316538;**  
**[ruth.noakes@homecall.co.uk](mailto:ruth.noakes@homecall.co.uk))**

## National campaign news

The MNDa campaigns team, aim to raise awareness so the needs of people with MND, and everyone who cares for them are recognised, and addressed by wider society. We welcome members, and supporters to campaign with us, to help create positive change to the lives of people living with MND, and their carers.

The Government's changes to health services, and provision are based on the idea of 'localism' - this means giving local people and clinicians more

## December gathering in Winsley

All welcome to join us for a 'one off' Reunion Support Group on **Friday 4 December, 1.30–3.30 pm**

At St Nicholas Church Hall Winsley,  
Wilts BA15 2LH

**Contact:** Daphne Cox on 01225 868224 to let her know you can come.

power to make decisions about the services they need.

Please join our Campaign Network to help us influence Clinical Commissioning Groups (CCGs), who have taken on responsibility for large NHS budgets. Health and Wellbeing Boards, based in councils, and reviewing how to join up services better, and Local Healthwatch bodies, who are promoting the voice of the public.

We will get in touch with you via email to give you ideas, and advice on how to start campaigning locally, and keep you up to date with our national campaigning work, such as the MND Charter.

To sign up please email: [campaigns@mndassociation.org](mailto:campaigns@mndassociation.org) or call 01604611684. You can also like 'MND Campaigns' on Facebook, and follow @mndcampaigns on Twitter.  
[www.mndcampaigns.org](http://www.mndcampaigns.org)

## Cake sale in Weston in aid of MND!

We are thrilled that the ladies of Milton Methodist Church have chosen the MND Association as their charity of the year! Please come along to Milton Methodist Church (2 Milton Hill, Weston-super-Mare BS22 9RA) on **Saturday 21 November, 10.30–12 noon**

for their first fundraising event of the year – there will be Bring & Buy Stalls and a cake stall. All welcome!

**Thank you so much** to all of you who have raised money for us – you are all amazing! Particular thanks go to Les Rowe, a previous Association Visitor in the area who recently left Weston for pastures new in Honiton. Through a concert held in Weston and donations from local people upon Les and his wife leaving the area, they raised a fantastic £1,280.00 for the Bristol and Bath Group. All the funds we receive go directly towards supporting local people living with MND – so thank you!

**We are thrilled that Isle of Wedmore Golf Club** in Somerset has selected the MND Association as their captains' charity for 2016. Mr Toni Ribi & Mrs Susan Tarry will become the club captains in December at their AGM; Jon will be attending to meet club members and tell them about our group and how we support local people living with MND. We look forward to bringing you more news on this next year.  
[www.wedmoregolfclub.com](http://www.wedmoregolfclub.com)

### MND Association regional conference in Bristol – 24 January 2016

You are all welcome to join us for a regional conference at the Aztec Hotel and Spa, Bradley Stoke, Bristol on 24 January 2015. The day is free for plwMND and their carers and Association Visitors to attend. Please register at the link below.  
<http://www.mndassociation.org/news-and-events/events/conferences/regionalconference/>

### Bristol & Bath Group contact details

**Group Leader/Correspondent: Jon Wellington**

[jon@mnd-bbww.org](mailto:jon@mnd-bbww.org); 07887 387724

**Digital Media Officer: Gareth Weaver**  
[gareth@mnd-bbww.org](mailto:gareth@mnd-bbww.org)

**Event Coordinator: Maria Baker**  
[maria@mnd-bbww.org](mailto:maria@mnd-bbww.org)

**Newsletter Editor: Becca Ramsden**  
[becca@mnd-bbww.org](mailto:becca@mnd-bbww.org)

#### Committee vacancies:

Group Leader  
Fundraiser  
Finance Officer  
General Volunteers

Winsley & Bath Support Group Organiser:  
**Ruth Noakes** 01225 316538;  
[ruth.noakes@homecall.co.uk](mailto:ruth.noakes@homecall.co.uk)

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  
0117 414 0803; [Helen.Madden@nbt.nhs.uk](mailto:Helen.Madden@nbt.nhs.uk)

Regional Care Development Advisor (Bristol & West): **Neil Drinkwater**  
[neil.drinkwater@mndassociation.org](mailto:neil.drinkwater@mndassociation.org);  
07831 349398

Volunteering Development Coordinator (South West): **Jo Campbell**  
[jo.campbell@mndassociation.org](mailto:jo.campbell@mndassociation.org)

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](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 Bristol & Bath 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.