

A Note from Our Group Chair, Andrew Grundy



As you can see we have a new layout for the latest edition of our newsletter: many thanks to Elane who has pulled it together. This edition is jam-packed, and two themes stand out for me.

Firstly, the many fundraising activities that have been successfully run by volunteers, some of which I have had the privilege of attending. What has struck me is the inventiveness and drive of many of our volunteers, and the generosity of people in these difficult economic times. The activities have provided a much needed boost to our bank balance.

Secondly, a great example of how funds are used to support people with MND; and here I'm talking about the opening of the MND Care Centre at Frenchay Hospital. A special word of thanks goes to Hilary Fairfield who has worked long and hard to make this a reality.

You'll see that we have more fundraising activities planned, so please remember we need all the help we can get – just give us a call.

I hope you enjoy reading this newsletter and like the layout. As always we are keen to hear your feedback, positive and negative, so please let us know what you think by dropping a line to either Elane or myself (contacts on back page).

AUTUMN 2012

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Sign The MND Charter



**The Motor Neurone
Disease Association
Charter**

On 1 June the Motor Neurone Disease Association launched its first ever Charter, a call for action setting out what **good care** looks like for people living with MND and their carers. The Charter aims to gain support from individuals and organisations with a personal or professional connection with MND, and work towards the vision of the right care, in the right place at the right time for people with MND and 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.

The MND Charter has 5 Aims:-

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

**If you'd like to contribute
something for the
newsletter please email**

Elane at

laney_laner@yahoo.co.uk



Photo Courtesy of Daniel Sprackman

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

New MND Centre at Frenchay Hospital

The official launch of the Bristol MND Care Centre on 30 June was a great occasion - the culmination of several years of negotiation and discussion between the Association and local health service managers and clinicians.

The launch was conducted by Richard Noble, OBE, a patron of the Association who is currently preparing for a 1000mph landspeed record attempt with his Bristol-based 'Bloodhound'. Richard has a huge interest in MND after his mother died of the condition, and has been a great supporter of the Association's work.

The reception at the lovely old Trust HQ building on the Frenchay Hospital site was attended by a number of people with MND and their families as well as clinical staff and representatives of local health services. Then all the guests made their way to the Neurology Outpatients department for a ceremonial unveiling of a wall plaque. Some rather bemused people were in the outpatients' waiting area when the horde of guests thronged into the clinic, photographers clicked away, and a BBC film crew turned up to record a piece on camera that was broadcast that evening on television.

The Care Centre Director and lead clinician is Dr Andria Merrison, a Neurologist based at Frenchay Hospital. She is working closely with **Sue Waldron-Smith** (the Care Centre Co-Ordinator) and **Hilary Fairfield** (the MNDA's Regional Care Development Advisor for



The Care Centre plaque – unveiled by Richard Noble, OBE

Photo courtesy of North Bristol NHS Trust

the West of England) to develop the Care Centre and make it into a centre of excellence.

"Establishing Frenchay as a specialist centre is a wonderful opportunity", said Dr Merrison at the launch. "We aim to promote a culture of clinical excellence", she continues, "in accordance with the MND Association standards of care, and to do this with sensitivity, compassion and kindness. We are extremely grateful to the MND Association for their very generous support. North Bristol NHS Trust now has greater resource to provide outstanding care for people living with MND and their families and carers. We can better support professionals and develop research locally and nationally."

"We aim to promote a culture of clinical excellence".

The MND Care Centre at Frenchay Hospital is now able to offer care to 140 people.

The official opening of the centre welcomed people living with MND and staff involved in making it happen.

Photo courtesy of North Bristol NHS Trust.



Frequently Asked Questions about the MND Centre at Frenchay Hospital

Where is the MND Care Centre?

The service is based in the neurology department at Frenchay Hospital, where the clinics will be held, but the Co-ordinator will link in with community teams across a wide area.

How is the centre funded?

The MND Association has provided funding for:

- a full-time care Co-ordinator for 4 years to provide help and support to people living with the condition and their carers and families
- some equipment
- a Respiratory Technician who will undertake breathing tests in the clinic rather than people having to travel to Southmead Hospital or the Bristol Royal Infirmary for these tests.

What happens at the Care Centre?

The team based at the Care Centre will:

- hold regular clinics for people who are suspected of having MND or who have been diagnosed with the disease
- provide advice and support for health colleagues in neighbouring counties
- link in with local community teams in a wider area
- provide an education programme for health professionals
- link in with research centres.

How often are the clinics held in Bristol?

There are two MND clinics held each month at Frenchay, and in addition, a clinic held once a month at the Bristol Royal Infirmary jointly with a respiratory consultant, for people with MND who need help with their breathing.

I currently see a Neurologist at a different hospital. Do I need to go to Bristol instead?

Your Neurologist may refer you to the MND Care Centre in Bristol if a second opinion is needed, if your care is complex, or if you request a transfer of your care.

Are there any clinical trials taking place in Bristol for people with MND?

Not at the moment, but there is an aim to increase the amount of research that people with MND can access in the area in the future.

To find out more about the Care Centre and what it has to offer, you can contact Hilary at the MNDA or Sue at Frenchay Hospital as follows:-

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

Sue Waldon-Smith, MND Care Centre Co-ordinator, Frenchay Hospital, 0117 340 2287 or via email suzanne.waldon-smith@nbt.nhs.uk.

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 and 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 and Weston area

Saturdays 2pm-4pm

Contact Ray Hulbert

☎ 0117 9755492

@ ray.hulbert@yahoo.co.uk

Saturday 29th September
Wyevale Garden Centre,
Thornbury

Saturday 27th October
Eden Grove Methodist
Church, Filton, Bristol

Saturday 24th November
St Peter's Hospice, Brentry,
Bristol

Saturday 15th December
Christmas Party!
Venue to be arranged



Olympic Light on MND

Unless you have been living on the moon this summer you won't fail to have heard from someone about the infectious mood of the country due to the Olympic and Paralympic Games we proudly hosted. But did you know that our very own Alistair the Optimist was the proud bearer of the Olympic Torch on its journey to the London 2012 Stadium?



Picture of Alistair with his wife Alice and the Olympic torch

Alistair undertook his part of the journey on 22 May in Glastonbury, along with his wife Alice. He later brought his torch to the Winsley Support Group to show everyone.

Charity Memorium Concert

A charity concert organised by the Salford Community Association was held on 23 June at Salford Hall in memory of David Roberts who passed away on 28 February. Celebrating David's love of music (he was conductor of the Salford Singers) the evening saw a variety of music performances of high standard and **raised £1150** to be shared between the MNDA and Dorothy House who both had representatives present to say a few words of thanks. David was an active member of his community and a regular member of the Winsley MND Support Group. The evening included a meal of steak and kidney pie, followed by apple pie and cream – David's favourite. It was a very enjoyable, and at times emotional evening.

Money Supermarket and Market! Get Involved with Our Fundraising Collections



Our Group has prime location at the 2012 Bath Christmas Market, (pictured) right next to the famous Bath Abbey!

WE NEED YOUR HELP

If you'd like to help us on the stall please read this article and get in touch!

On a wet, windy Saturday in early August some members of our committee group, along with members of Eden Grove Methodist Church, met at Tesco's supermarket, Golden Hill, to collect money on behalf of MND. One of the volunteers from the church, Ruth, stayed for the whole 8 hours – not bad for a person aged 92! It was a long day but well worth the effort as we **raised £469 for MNDA!**

This is fantastic and will really make a difference to the support we can provide. Thank you to everyone who helped out and donated on the day!

In addition to our supermarket collections we have secured a space at the Bath Christmas Market this year! This is very exciting news for us as a group as we will be there on the busiest Saturday of the **Bath Christmas Markets, Saturday 1 December.**

If you, or someone you know, would like to lend a hand on our stall for a small part of the day, please get in touch with our Group Secretary **Sue** via email on sue@chartax.biz. We also need some raffle prizes so if you have something you'd like to donate, please get in touch. Thank you!

The 27th Annual General Meeting of the Motor Neurone Disease Association took place on 15 September 2012. Visit the MNDA website www.mndassociation.org.uk for information about the past year and the year ahead.

Volunteers Required!

*Collections at local supermarkets can really make a difference to our bank balance, and subsequently to the lives of people living with MND. If you'd like to help us with local collections in the future, including getting involved with manning the Bath Christmas Market stall, please do get in touch with us so that we can register your interest. The more people we have helping, the more money we can collect! Please contact our Group Secretary **Sue** if you are interested via email on sue@chartax.biz*

An Invitation to the Palace by Daphne Cox, Association Visitor and Coordinator



Daphne Cox (right) with her niece Valerie Hemmings in the garden at Buckingham Palace.

On a rare sunny but warm afternoon my niece Valerie and I headed for Buckingham Palace, not as tourists but as a guest of Her Majesty the Queen, in her Diamond Jubilee Year. The MND had nominated me to be the one representing our charity. What an honour!

We arrived on time for 3pm and joined the queue for security check. Then we headed across the forecourt to the Palace, through the main gate to the quadrangle and onto the lawns at the back of the Palace.

We mingled with hundreds of other beautifully clad guests as we walked around the whole garden, listening to the music. We then prepared to stand in line for the Queen's arrival.

The band struck up the National Anthem and the Queen and Prince Phillip, Princess Anne and Prince Andrew arrived.

Some guests were presented to the royal party. Following this Valerie and I went off for a wonderful tea laid out in a magnificent marquee. As we finished tea I wondered if I could speak with Princess Anne, our Patron. After I had asked if it was possible I was duly presented to her!

It was lovely to chat with Princess Anne, who told me of her interest in MND and the place research had. It was a real honour, on what was a glorious English summer day, rare so far this summer, to enjoy this Royal privilege.

Valerie and I continued to mingle until after the Royal party left and by 6pm we exited the same way we entered, marvelling at the wonderful experience.

Thank you to the MNDA for nominating me and letting me enjoy this wonderful occasion!

Become an Association Visitor (AV) and make a difference!

Association Visitors (AVs) perform a vital role in supporting people living with MND and those close to them. AVs are based in the local community and they listen and support those living with MND and their families, discussing the effects of MND and what Wider support is available. Sadly there are people living with MND in the East and South Bristol and Bath areas who currently do not have an Association Visitor available for them. If you think this is a role that you would like to take on, or you know someone that might, please get in touch with our Group AV telephone line (details in the blue box) or contact **Hilary Fairfield, Regional Care Development Advisor**, via email hilary.fairfield@mndassociation.org or telephone **08453 751828**.



We are particularly short of AVs to cover Bath and the East and South areas of Bristol.

Support for Association Visitors

It is important that Association Visitors (AVs) get together from time to time in order to feel that they are part of a team and gain wider support from National Office. If you are already an AV and would like to register for the next AV Support Day (date to be confirmed) or if you are considering taking on a role as an AV but would like to find out more please contact our Group AV telephone line **07516 023675**. Full training will be provided.

A Night of Wizardry

As part of our efforts to continue to raise awareness and funds for the Motor Neurone Disease Association our committee member Ray Hulbert arranged a musical concert on the evening of Friday 27 July.

Byron Jones, the international organist, played the Compton Wizard Organ at Eden Grove Methodist Church Hall in Filton, Bristol. Byron, or The Welsh Wizard, as he is often known, treated those in attendance to an evening of organ classics ranging from "The Dam Busters" to "I Do Like To Be Beside The Seaside".

The Compton Wizard Organ at Eden Grove

The Compton Organ is an original from a 1920s British picturehouse in Leytonstone which was salvaged from being shipped abroad and has been lovingly restored section by section whilst maintaining its original walnut wood finish. The Compton Wizard is now proudly housed beneath the Eden Grove Methodist Church Hall. And, just like the organ at Blackpool, it rises from the floor as the organist makes their entrance.



Byron Jones the Organist, pictured with the Compton Wizard, which he helped carefully restore within the Eden Grove Methodist Church, Filton, Bristol.

Also present at the evening was Her Majesty's Lord Lieutenant of Bristol City and County, Mrs Mary Prior and her husband John.

The music was very much enjoyed by those present and a grand total amount of £240 was raised on the evening so well done and thank you to everyone who contributed.

Thank you to all those that attended and a special thank you to the Welsh Wizard himself, Byron Jones, for entertaining us all in such a fabulous fashion.

And, if you missed the event this time around we will keep you posted of any future events the MNDA plans at Eden Grove so you can experience this wonderful form of entertainment for yourself. It really is truly spectacular!

Cake Bake

As part of the evening a local schoolboy Oliver Woodland, from Bromley Heath Junior School, was invited along to present our Chairman Andrew Grundy with a **cheque for £125!** Oliver's grandfather had passed away some years ago after living with MND and Oliver had decided to raise some money for our group to help others. The funds were raised by Oliver himself when he decided to sell his toys, undertake household chores, make some cakes and sell them, and donate all proceeds to the MNDA.

Thank you to Oliver for all his hard work in raising money for our cause.

Oliver Woodland with Her Majesty's Lord Lieutenant of Bristol City and County, Mrs Mary Prior, at the Organ Recital in Eden Grove Methodist Church, where Oliver presented his donation.



Tockington Family Fun Day

On Saturday 30 June a family day out was organised by one of our Association Visitors, Dianne. Despite the wet weather, there was a good turnout and lots to enjoy, with activities ranging from learning the skill of archery, having your face painted, eating homemade cakes and listening to the local folk band. Bric-a-brac, plant and book stalls, were among the stalls to raise **lots of money** with **lots of awareness about MND** being raised too. Well done Dianne for all your efforts in organising the day and thank you to everyone who helped her and those of you that turned up. And thank you, too, to Dan Sprackman, who took these marvellous photographs!



All the fun of the Tockington Family Fun Day in June, photos courtesy of Dan Sprackman



The Feet of Bodmin

Congratulations to our Group Secretary, Sue Paulley, her husband, friends and members of the MNDA in Cornwall who all stomped across the Ten Tors in Bodmin earlier this summer to raise money for our charity! The Bristol, Bath, Weston and Winsley Group teamed up with Cornwall to undertake the challenge and even the sun came out to help them along!



Our Group Secretary Sue Paulley (far left) with members of the Cornwall MNDA Group, Sue's husband Nick (far right) and friend Viv Henwood (centre), whose brother Les lived with MND

And the votes are in!

If you recently voted for the Board of Trustees of the MND Association, the results can now be viewed online at www.mndassociation.org.uk.

If you can help a little,
we can change a lot.

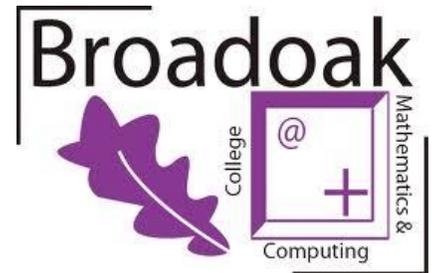
Sign up to the **MND Association Campaign Network** for details about our campaigns and how you can get involved. Find out more online by logging onto

[www.mndcampaigns.org/
campaign_network](http://www.mndcampaigns.org/campaign_network)

or if you haven't got a computer, contact **Raj Johal** on **020 8551 2152** for more details.

Broadoak Helps It All Add Up by Ray Hulbert, Support Group Organiser

Leaving Bristol at 715am I travelled down the M5 to the Broadoak Maths and Computing College in Weston-super-Mare to meet with the Senior Tutor for Years 7 and 8, Mrs Sara Allen on MND business! I was taken to the Main Hall to meet around 100 or so students. Over the last few months they have been holding special events to raise money for Motor Neurone Disease. These events have included cake sales, walks and even sponsored silences, to name a few activities! I was presented with a **cheque for £525.32** for which the Association is extremely grateful. I thanked them for their efforts and for choosing MND as their charity of the year. **Thank you Broadoak.** You've really helped make a difference.



Contacts

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>

And many details are on our website at www.mndassociation.org

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.biz	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 Anne House 51 Rodbourne Road, BS10 5AT ☎ 0117 382 0413
Newsletter Co-ordinator Elane Relford @ laney_laner@yahoo.co.uk	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	
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

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.