

Useful Numbers

MNDConnect 08457 626262

N Wilts Group website
www.mndnorthwiltshire.org.uk

MNDA Volunteering Team
01604 611681

Hilary Fairfield
Regional Care Development
Adviser: **08453 751828**

Lucy Etheridge
Volunteering Development
Co-ordinator: **08453 751839**

Sarah Hampton
Regional Fundraiser, South
West: **01237 451925**

Prospect Hospice
01793 813355

Support Meetings

We hold support meetings in Swindon and Calne.

Swindon meetings are held at The Lawns Community Centre Guildford Road, Swindon from 2.15-4pm. The next ones will be 18th September and 20th November.

Calne meetings are held at The Masonic Hall, Stainer Road, Calne from 2.15-4pm. The next meetings will be 15th August and 17th October.

For **both meetings** contact Moya Wallis on **01380 859611** or email moyawallis@hotmail.com

All sessions are drop in. Come along to share ideas, meet other members and for a change of view! Volunteer helpers also welcome.

Newsletter

Autumn 2013

ISSUE No 22

Chair's welcome

I would like to say a huge Thank You to all who have helped us make the June Month of Awareness such a success. We set ourselves a target to complete 25 events to raise awareness of MND, and I'm delighted to report that we smashed this and raised just short of £3,000 too, doubling the amount raised during June last year. Lots of you helped by holding Bake it events, took part in Walk to d'feet, saved loose change in collections boxes and one family organised a half marathon for their grandchildren. Thank you all so much for your support.

We are delighted to welcome Susanne as a new Association Visitor and you can read about her training in this issue.

Fundraising is a vital part of our work and we would love to hear from you if you feel you could help us with this.

Hope you enjoy reading this issue and do let us have your news and views.

Alison Aviss

June Round-Up

Fundraising activities:

- ◇ Reed Family toddlers' half marathon (this issue)
- ◇ Walk to d'feet—raised £250
- ◇ Six Bake It events, including one by Saskia (this issue)
- ◇ Various people collected loose change in MNDA boxes
- ◇ Raffle tickets sold for national MNDA draw
- ◇ A town centre collection
- ◇ Stall at Wootton Bassett

Other activities included:

- ◇ Talk to the Scouts by Paul

- ◇ Three committee members attended and spoke at the Regional Forum
- ◇ The Group sent out cards to mark Carers' Week

And of all this was gossiped on Facebook and Twitter.



Well done everyone!

Round-up

Never too young

Tegan, Archie, Mason, Taylor and Finley, aged between 2 and 5 years, are putting most of us to shame. When their great-grandmother, Cherry Reed, was diagnosed with MND, they decided to take on the challenge to walk a half marathon - 13 full-size miles - to raise money for the MNDA.



Accompanied by their family, the youngsters covered the distance over three weeks in one mile sections, finishing on 1st June. ↗

The children have raised £1,300 from friends, family and passers-by. "They have all been wearing t-shirts with the MNDA logo on. As we've been walking around a lot of people have stopped and asked what they are doing and giving donations", said Sharon Wallis, grandmother to four of the children.

The funds they have raised will make a real difference. Very well done.

Corsham 10K

810 runners took part in the 29th Corsham 10k run on St George's Day, in memory of former fire fighter Martin O'Shea (whose story appeared in the last issue).

Alison received a cheque for a staggering £5,500 on behalf of the Association.

Generous sponsorship cheques were also received from the Rudloe Social Club (£1,200) and from Malcolm Eadie (£382).

'Arthur's Open House' - the team raised £283 with a Bake It event and gathered 20 signatures for the Charter.



Making waves on the radio

In May BBC Radio Bristol kindly ran a workshop to train some MNDA volunteers and staff in how to get our news onto local radio (and papers).

Jill Moody, a highly experienced news editor from BBC Northampton, led the day. She began by posing the question, what is news? Her answer: it is about telling stories, and particularly stories with a personal slant. Corporate stories are all very worthy, but people want to hear about people! The best 'hook' for local press or radio will be a personal story.

Jill believes that both plwMND and their carers have stories to tell which will interest and engage. She wondered if Groups are over-cautious about asking people if they would be willing to be interviewed – rather a frightening word. Interviews can be recorded and edited to reduce the stress! Could you consider doing this?

Phone-ins are a great way of getting the MND message out. In a sense they are just like a conversation, with people chipping in when they want to. Anyone can phone in and say their piece.

Twitter offers new opportunities. Local radio monitors social media for news (as they have so few reporters). And get ourselves into the local radio station's events guide.

All in all, a very worthwhile day.

Local support for local people

On Becoming an AV

by Susanne Webb

I worked for a major financial institution for many years, and 10 years ago started my own part-time holistic therapy business. When I was made redundant four years ago, I offered my services voluntarily to Prospect Hospice, which I found rewarding. While there I met some plwMND and their carers. This encouraged me to help with support group meetings and with fundraising. In the process I met the N Wilts 'team'.



I was looking for something worthwhile and wanted to help people. So when I saw an advert for volunteer AVs, I was interested.

The role is about being committed to a plwMND and

their family, about listening, showing empathy, providing information about professional services, equipment and benefits. The MNDAs asks for an initial commitment of 4-5 hours a week for a minimum 18 months. Then review ...

The MNDAs accepted me for training. I attended a short but very focussed course, and was given a vast amount of reading to get my head around. Later this month I hope to shadow Alison and Moya, our AVs, on their visits. Then I will be allocated a newly diagnosed person to work with! Hilary (from MNDAs) and my fellow AVs will be there to support me.

How do I feel? Daunted at the role. Humbled that a family will let me share their emotional journey. It will sometimes be hard for me – but not as hard as for them! And definitely 'worthwhile'. I will let you know how I get on.

If you would like to know more about the AV role, contact Alison on 07976 155635.

Alison's story

Alison Aviss, Group Chair and one of our AVs, has talked about the challenges and blessings of her role. Read what she has to say on the MNDAs website at <http://www.mndassociation.org/get-involved/volunteering/volunteering-case-studies/Alisons%20Volunteering%20Story> (Sorry the address is so long! Ed.)

Fundraising

Saskia 'Bakes It'

Steyning Grammar School year 8 pupil Saskia Foulds-Holt (whose Grandmother had MND) held a 'bake it' event on Tuesday 25th June. Saskia, a keen baker and avid fan of the Great British Bake Off, made chocolate brownies, chocolate crispy cakes and a selection of cookies, and with the help of her close friends sold them to fellow students at 40-50p during their morning break, raising an amazing £65!

Pictured with her signature dish, brownie, Saskia wants to be an entrepreneur and hopes one day to have a global brand. She is going to take GCSE business studies to further this aim and next week she is meeting Lord Alan Sugar as part of a school project!



Well done and thank you for supporting us Saskia. We think your Grandmother would

Sharon Lloyd and 6 family members are running the Royal Parks Foundation half-marathon on 6th October for MND. If you would like to make a donation or sponsor Sharon, there is an online charity giving site www.virginmoneygiving.com/ SharonLloyd

Meet your Local Support Team

Hilary Fairfield

HILARY is the MND Association's Regional Care Development Adviser (RCDA) for the West of England.

Contact Hilary by phoning **08453 751828** or email hilary.fairfield@mndassociation.org

Association Visitors

THE North Wilts. Group currently has two Association Visitors (AVs):

Moya Wallis

CONTACT Moya on **01380 859611** or email moyawallis@hotmail.com

Alison Aviss

CONTACT Alison on **07976 155635** or email alisonaviss@btinternet.com

Regular support meetings are held in Swindon and in Calne. See the front of this Newsletter for dates and venues.

National Round-up

MND Charter

Raise the profile of plwMND with politicians. Register your support by signing the MND Charter online. Go to www.mndassociation.org then select 'Helping us' and 'Campaigning'.

Film release — *I Am Breathing*

A documentary capturing the final months of the life of Neil Platt has been released. Described as 'hard-hitting yet thoughtful', copies on DVD may be booked online at www.mndassociation.org/iambreathing.

Funding — How its spent

The national Association recently announced its income for 2012/13 as £13.3 million — all from fundraising.

- 78% spent on research, care and campaigning
- 19% spent on fundraising - £3.70 generated for every £1 invested
- 3% spent on central administration



Registered Charity No 294354

We never lose hope. We strive to find a cure for MND, and to support everyone affected by this devastating disease

Support for You

What's On?

27th July

Charity stall, Malmesbury cross, 8.30am—1pm

1st August

Committee Meeting, Prospect Hospice, 7pm

15th August

Calne Support Meeting, Stainer Road

5th September

Committee Meeting, Prospect Hospice, 7pm

14th September

Collection, Sainsbury's Bridgemoor

18th September

Swindon Support Meeting, The Lawns

3rd October

Committee Meeting, Prospect Hospice, 7pm

17th October

Calne Support Meeting, Stainer Road

7th November

25th Anniversary Celebration

16th November

Collection & stall, West Swindon Centre

20th November

Swindon Support Meeting, The Lawns

Keeping in Touch

For those who don't wish to email, please write to: **North Wiltshire Group, c/o MNDA, PO Box 246, Northampton NN1 2PR**

Don't forget you can follow us on Facebook at <http://www.facebook.com/MNDNorthWiltshire> on Twitter [@MNDNorthWilts](https://twitter.com/MNDNorthWilts) and via our website www.MNDNorthWiltshire.org.uk

This is YOUR Newsletter. If you have any comments, suggestions or news items please do contact me on AndrewRSargent@gmail.com

The deadline for submission for the next issue will be **5th October 2013**.

Andrew Sargent