

## 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 16th March and 18th May. Contact Susanne Webb on **07776 126994** or email **susanne.webb@gmail.com**

Calne meetings are held at The Masonic Hall, Stainer Road, Calne, from 2.15-4pm. The next meetings will be 18th February and 21st April.

Contact Anita Creamer on **07827 421035** or email **bilanitawill@btinternet.com**

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

## Chair's welcome

A very Happy New Year to you all. As the year starts we are busy setting our goals and actions for 2016 and looking back at the achievements for 2015. We identified 43 actions that we wanted to achieve in 2015 and fully completed 40 of these and partially completed another. This equates to an amazing 94% achievement rate. *Read more about this in Our Impact Report (p 2).*

These achievements have only been possible due to your help and the dedication and commitment of the volunteers who make up the North Wiltshire Group team, who share a common goal to make a real difference to all those affected by MND.

A massive **Thank you** to all.

We hope you enjoy this issue. Do let us have your news and views.

*Alison Aviss*

## ***Mrs Scrumps Christmas Market***

The Christmas Market at Dauntsey Park was great and the event raised over £1,000 to be split between MND North Wilts and The Eve Appeal. Our stall raised £479.75 on the day and a further £233.05 in advance sales, making a total of £712.80. In addition, we received £705 from the event.

Many thanks to all our supporters - Susanne, Alison, Anita, Barbara and her daughter Sharon, Sue and Sarah Occleshaw who all made items to sell and also helped on the day. Also a huge thank you to all our knitters and sewers who made all the lovely things for us to sell. A good day was had by all.



## North Wiltshire Group—Our Impact in 2015

This year, we continued the work we first started in January 2013 by developing an action plan to help us focus our activities, assist in maximizing our resources and skills and to provide a mechanism to identify and celebrate our successes.

The 2015 action plan focused on **5 key areas:**

- ⇒ Support for people with Motor Neurone Disease
- ⇒ Awareness Raising
- ⇒ Fundraising
- ⇒ Campaigning and Influencing
- ⇒ Group Organisation

Supporting national initiatives and projects of the MNDA is a priority for us, and as such, a number of our group members have taken part in working parties to help develop national strategy that we can introduce locally.

### How did we do?

- ◇ The 2015 plan detailed 43 individual actions
- ◇ 40 actions were successfully completed
- ◇ 1 action was not fully achieved. The Group work was completed but the collaboration with others required to achieve this aim was not fulfilled
- ◇ Equates to a 94% achievement rate
- ◇ Collectively, our Group volunteers gave over 4,500 hours of their time
- ◇ Progress this year has been affected by changing circumstances locally and the retirement of some volunteers

### Here are some examples of our achievements

- ◇ We directly supported over 45 local families affected by MND and worked closely with our new Regional Care Development Adviser
- ◇ We provided over £8,500 in financial assistance to local families towards the cost of home adaptations, specialist equipment and quality of life Improvement
- ◇ In addition, the committee elected to send £10,000 to the MNDA national office: £5,000 towards the introduction of a Carers Grant fund and a £5,000 contribution to Volunteering Development
- ◇ Following our success in promoting the Charter, our team was invited to attend the celebration event following presentation of this to Parliament in June. Building on this, we have been developing a relationship with the Minister for Disabled People, Justin Tomlinson who is a Swindon MP
- ◇ We worked closely with NHS professionals to build a successful business case for the specialist MND post created in 2014 to be made permanent and fully funded and are very grateful for the forward thinking of the North and East Wiltshire Clinical Commissioning Group who agreed this in June

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*Local support for local people*

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We are currently identifying opportunities for future development and finalizing our action plan for 2016, which is likely to be more challenging than this year!

These achievements have only been possible due to the dedication and commitment of the volunteers that make up the North Wiltshire Group team, who share a common goal to make a real and positive difference to

all those affected by MND in our area. If the c. 4,500 hours given by our volunteers were paid at the UK living wage hourly rate it would cost over £35,000!

Thank you all so much.

If you would like to help us with this important work we would love to hear from you. Please contact us at [info@mndnorthwiltshire.co.uk](mailto:info@mndnorthwiltshire.co.uk) or call us on 08457 626262.

### **Giorgio's ambitious challenge**

Giorgio Rigali has set himself the ambitious challenge of completing 16 sport and fitness events in 2016, including marathons, triathlons and three peak climbing.

Giorgio's four year old niece, Freya, suffers from Rett Syndrome, a disease involving neurone dysfunction. He has also learned that his friend's father is living with MND.



Giorgio & Freya

As a keen fundraiser and fitness fanatic, Giorgio is determined to

support two charities, Rett UK and MNDA, dividing any money raised equally between them.

"The challenge will take its toll but I find sport a stress reliever and the motivation to help out the charities will push me through," said Giorgio.

Anyone who wishes to donate to his cause can visit the website [uk.virginmoneygiving.com/GiorgioRigali](http://uk.virginmoneygiving.com/GiorgioRigali).

(source: Swindon Advertiser 21 January 2016)

### **Anita Sinclair Interview**

Anita Sinclair's post at the Great Western Hospital has been a success story. Her innovative role aims to offer patients and their families a co-ordinated approach to their complex care needs. When Anita, a respiratory specialist physiotherapist for neurological conditions, was interviewed for the Chartered Society of Physiotherapy's January online newsletter, she was able to talk not just about challenges but about successes. Initially the post was for one year, part-funded by the North Wiltshire Group of the MNDA (with money raised in memory of Martin O'Shea), but funds have now been found to continue it.



Anita's top tip to fellow professionals is, 'Don't sit in traditional roles; apply for posts that often go to other disciplines. This will open up opportunities and a platform to set up new initiatives.'

Read Anita's interview at <http://www.csp.org.uk/frontline/article/3-minutes-anita-sinclair>

## Useful Contacts

**N Wilts Group website**  
[www.mndnorthwiltshire.org.uk](http://www.mndnorthwiltshire.org.uk)

**N Wilts Group contact**  
[info@mndnorthwiltshire.org.uk](mailto:info@mndnorthwiltshire.org.uk)  
or phone MND Connect

**Facebook** <http://www.facebook.com/MNDNorthWiltshire>

**Twitter** @MNDNorthWilts

Letters will be forwarded from:  
**North Wiltshire Group, c/o MNDA,**  
**PO Box 246, Northampton NN1 2PR**

**MNDConnect 03457 626262**

**MNDA national website**  
[www.mndassociation.org](http://www.mndassociation.org)

**MNDA Volunteering Team**  
**01604 611681**

**Neil Drinkwater, MNDA Regional Care Development Adviser, email**  
[neil.drinkwater@mndassociation.org](mailto:neil.drinkwater@mndassociation.org)  
**mob: 07831 349398**

**Prospect Hospice 01793 813355**

**Dorothy House 01225 722988**

### Other fundraising included:

The Royal Wootton Bassett charity stall regularly continues to raise valuable funds for the Group.

A successful stall and collection was held at West Swindon Shopping Centre on 21st November.

In December a whist drive organised by Ruby Collison raised £200.

Barbara Sargent and the ladies of Sandon (Staffs.) knitted over 100 Christmas stockings which were sold at Mrs Scrumps Christmas market and elsewhere

A very well done to all who helped.

The deadline for submission for the next issue of the Newsletter will be **9th April 2016**.

*Andrew Sargent*

## What's On?

### 18th February

Calne Support Meeting, Stainer Road

### 3rd March

Committee Meeting, Prospect Hospice, 7pm

### 16th March

Swindon Support Meeting, The Lawns

### 7th April

Committee Meeting, Prospect Hospice, 7pm

### 21st April

Calne Support Meeting, Stainer Road

### 18th May

Swindon Support Meeting, The Lawns

### Members of the North Wilts group attended the recent MNDA regional conference in Bristol.

Staff from David Niven House, MNDA Trustees, people with MND, health care professionals, Association Visitors and volunteers met to hear and discuss the success and future plans of the Association. The day was very informative covering topics including campaigning, research, wheelchairs and care for people with MND. Information stands offered literature and the opportunity to talk to Association staff. The conference was live streamed and can be viewed on the MNDA website.



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