

## 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 20th March and 29th 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 20th February and 17th April. 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.*

**Don't forget the MND Charter.** Go to **www.mndassociation.org** then select 'Helping us' and 'Campaigning'.



## Chair's welcome

We hope that you all enjoyed the festive season. The New Year is always a time for reflection and review and for some the making of resolutions. Last year, for the first time, our group set out a plan of action identifying all the things we hoped to achieve and to give us a focus of where and how we should organize our resources.

As we go to press, we are reviewing our progress and will include a full report in the next issue. However; I am delighted to say that we are very pleased with our progress and what we have achieved within the year.

One of our key aims is to raise money in order to be able to support local families, and with your help 2013 was a very successful fund raising year. We share some of the headline details of the difference your support has made to local people and we thank you all sincerely for your continued support.

Enjoy reading our newsletter.

*Alison Aviss*

## Achievements in 2013

Sally Light, CEO of the MNDA, has picked some national highlights of 2013.

- ◆ Working together, we have achieved a lot in the areas of support, fundraising, research and awareness raising
- ◆ Nationally, AVs have supported 1,288 plwMND.
- ◆ 1,022 pieces of equipment were provided to help people with day-to-day tasks and communication.

- ◆ National office agreed to 422 requests for financial help totalling £394k, while local Groups were able to give a further £586k.
- ◆ The MNDA funded 62 research projects and co-funded three clinical fellowships.
- ◆ The film *I Am Breathing* was watched by thousands, raising awareness.

Our challenge is to build on our achievements in 2014!

## Fundraising

### Mrs Scrump's Market

The beautiful Dauntsey Park House [www.dauntseyparkhouse.co.uk](http://www.dauntseyparkhouse.co.uk) hosted a Christmas Market on 3rd December in support of MNDA. Organiser Susannah Dibben's father has recently been diagnosed with MND and is receiving support from our colleagues in Rutland.

There were lovely craft stalls selling leather goods, scented candles, jewellery, art work and Mrs Scrumps provisions and home-ware. Special thanks go to Glen Woodman who supplied many hand-knitted items for our stall. Special thanks also to Sue, Sarah and Lucy Occleshaw who baked Christmas biscuits and chocolate brownies, knitted some lovely Christmas toys and also served on the stall. The day was a huge success.

Many thanks to Susannah her enthusiasm and for the lovely venue.

### Buckets of cash

The collection at the West Swindon Centre on 16th November raised £638! Well done to all our volunteers.

Over the Christmas period several supporters raised money by selling Christmas cards, knitted items and cake. Well done.

### Ruby's silver presentation

Ruby Collison, an active supporter and a founder member of the Group, sadly missed the 25th Anniversary event. Her certificate, flowers and a small memento brightened up her stay in hospital.



## Summary of local support given in 2013

One of the key aims of North Wiltshire Group is to raise money and assist local people affected by MND to live at home and with dignity. This often requires some adaptation to the property, use of specialist equipment and help with transport. We are so grateful for all the fund raising efforts that go on all year round and the help we receive from our supporters. This makes it possible for us to help local families, and during 2013 we helped local people as follows:

£7,000	Between 3 families	For home adaptations
£2,150	Between 3 families	For specialist equipment
£ 360	3 individuals	Funded places for Health & Social Care Professionals to further their knowledge of MND
£ 250	1 family	For mobility assistance
<b>£9,760</b>		

In addition to this, during December we sent **£10,000** to the Association national office to assist with funding things that we cannot organize locally. These include: research projects, the cost of producing the printed materials we send to our families and the provision of specialist equipment that is loaned by the Association. We asked the trustees to use this money on our behalf for vital projects and are very proud that because of your help we have been able to do this.

*Local support for local people*

## Planning a bedroom/wetroom – key decisions

*by Colin Moss*

At some stage people living with MND (plwMND) may need to consider changes to their home environment to suit their changing needs. Probably the most important room to consider is the bathroom. Discuss your situation with your OT and get their advice and help. Wherever possible, plan ahead so you get things in place in time for when you need them.

1. We obtained three quotes but opted for a builder recommended by my brother.

2. We thought carefully about the layout, making sure of adequate wheelchair access, that the doorways were wide enough and all on one level.

3. A new entrance lobby with cupboard gives storage space for wheelchair and mobility scooter and ramp to the driveway outside.

4. The new bedroom has wide, level access French doors (with a ramp to the rear garden). We allowed plenty of space around the bed for wheelchair turning. The ceiling has extra support beams to facilitate a ceiling hoist from the bed into the wetroom (if needed in the future).

5. The wetroom was laid out after discussion with my OT. I decided to raise the toilet pan by 2" on a plinth to make getting to my feet easier even though my OT warned that raising the height would mean a commode wouldn't fit over (if needed in the future). We fitted a Bio Bidet wash/dry toilet seat, which I would recommend.

6. We considered a wall-hung basin but decided on a large sink on a pedestal, which suits wheelchair use fine at less cost. Quarter turn lever taps are easy to turn.

7. We opted for a thermostatic triple shower valve with lever handles, overhead rose and a diverter to hand-held hose giving two options, plus a pull-down shower seat with legs which is fixed to the solid wall (rather than to studwork).

8. One of the most important things was

the wetroom flooring. Kits are available which ensure the slope is correct, but they are expensive, so the plasterer made a slope in the floor screed of around 1 in 40 down to the drain, which prevents flooding the entire wetroom whilst not being too steep to walk on when wet. We choose the Polyflor brand floor covering with tiny raised 'studs' (designed for permanently wet areas), as these give better grip when wet. It was cheaper than the Altro brand equivalent. The wetroom floor works perfectly without the need for a shower curtain or screen. A stand-alone half-height screen can be added if I need a carer to assist (to save the carer from getting wet).

9. Finally, I will decide on the grab rails after fitting the shower stool. We are considering a body drier as drying myself is getting more difficult.

We did not qualify for a Disabled Facilities Grant, but the MNDA generously contributed towards the cost of the wetroom.

*Colin's thoughts regarding stair lift versus through-floor lift will appear next month.*

*Colin was diagnosed with MND in 2002—Ed.*

### MND on TV

In December the MNDA screened its first ever TV advert to raise awareness and to invite donations.

TV presenter Nick Knowles provided a voice for Eric Rivers who is living with MND.

The 60 second advert can be viewed on **YouTube**, or go to the MNDA website [www.mndassociation.org](http://www.mndassociation.org) and then select 'News & Events', 'Features', 'Our first ever national TV campaign'.

## Useful Contacts

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

N Wilts Group contact  
Moya Wallis 01380 859611

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 08457 626262**

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

**MNDA Volunteering Team  
01604 611681**

**Hilary Fairfield, MNDA Regional Care  
Development Advisor 08453 751828 or  
[hilary.fairfield@mndassociation.org](mailto:hilary.fairfield@mndassociation.org)**

**Prospect Hospice  
01793 813355**

**Dorothy House  
01225 722988**

### Corsham Choir

The wonderful Corsham Choir raised just over £285 for MND North Wiltshire when they sang at Sainsbury's just before Christmas. Well done all and thank you to all the generous shoppers.



## Support for You

### What's On?

#### 6th February

Committee Meeting, Prospect Hospice, 7pm

#### 20th February

Calne Support Meeting, Stainer Road

#### 6th March

Committee Meeting, Prospect Hospice, 7pm

#### 20th March

Swindon Support Meeting, The Lawns

#### 3rd April

Committee Meeting, Prospect Hospice, 7pm

#### 12th April

Charity stall, Malmsbury

#### 17th April

Calne Support Meeting, Stainer Road

#### 29th May

Swindon Support Meeting, The Lawns

#### 19th June

Calne Support Meeting, Stainer Road

#### 17th July

Swindon Support Meeting, The Lawns

### New diagnosis aid for GPs

A prompt, reliable diagnosis is vitally important for planning and care. The MNDA has been working with the Royal College of General Practitioners on an early diagnosis Red Flag tool for MND. The purpose of the tool is to raise awareness of MND with GPs and to help them make an accurate and speedy referral to a neurologist.

Other healthcare professionals will also find the Red Flag tool valuable, as they may be the first to notice the signs of MND in a patient.

**This is YOUR Newsletter. If you have any comments, suggestions or news items please do contact me on [AndrewRSargent@gmail.com](mailto:AndrewRSargent@gmail.com)**

The deadline for submission for the next issue will be **6th April 2014**.

*Andrew Sargent*

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**