

## 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 19th March and 21st 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 19th February, 16th April and 18th June. 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.*

## Chair's welcome

We hope that you all enjoyed the festive season (it seems a long time ago!). 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 2014 was a very successful fund-raising year. We thank you all sincerely for your continued support.

Enjoy reading our newsletter.

*Alison Aviss*

## The Theory of Everything

*The Theory of Everything* is the Oscar-tipped romantic drama about the relationship between Professor Hawking, the astrophysicist who is living with MND, and his wife Jane. Members of the MND North Wilts Group were invited to make a collection as the excited filmgoers left the first showings at Shaw Ridge Cineworld, Swindon. As well as raising funds, the film is valuable in raising awareness of the disease to a wide audience.

Chris Wade from the MND said: "It's a great opportunity for our members to share awareness of MND, and this is a great start to 2015. Professor Hawking is one of our Patrons and was involved when the Association was founded 36 years ago. His achievements while living with

MND are remarkable."



*Volunteers at Cineworld*

## Cardwave donation

As part of Cardwave's 10 year celebrations of being in business, Paul Norbury, Cardwave's CEO, has generously offered to donate £100 each month over the next 10 months to a different staff member's charity of their choice.

Staff members are picked out at random each month through various fun activities and challenges. February's decision was made through a game of bingo where Lois McGuffog, our Head of Operations, won the chance to donate £100 to her charity of choice. Lois' chosen charity is the MNDA North Wilts Group which has become very important to her following the diagnosis of a family member.



Lois commented, 'I am delighted to have the opportunity to donate to MNDA. Without the local team we would not have had the support which has been invaluable to my family — from providing practical help with equipment to liaising with local services to give us the help required to manage the disease. The North Wilts Group provides emotional and financial support through AVs and signposts advice and services. It also helps to raise awareness.

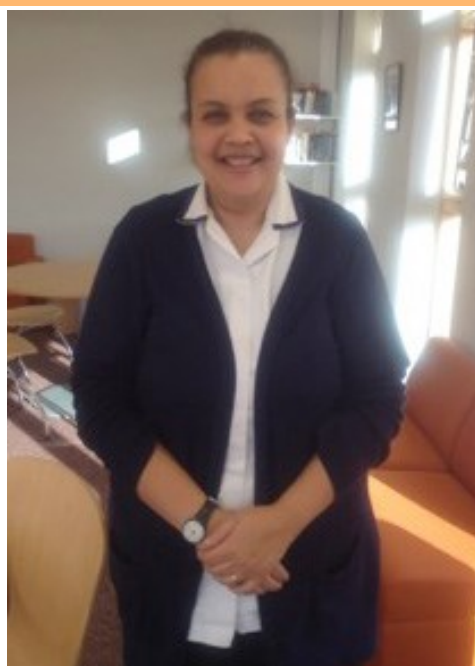
A £100 donation can provide vital information to ten people diagnosed with MND.'

## Make your voice heard

The MND Association has launched its General Election campaign to get MPs and prospective parliamentary candidates to commit to meeting the communication challenges faced by people living with MND.

The campaign has been launched with an e-action to persuade MPs and candidates to read the manifesto, 'Don't let me die without a voice', fronted by Charlie Fletcher, who is living with MND. The manifesto describes the number of people living with MND who will need communication support and illustrates the difficulties people have getting access to this support. The e-action aims to raise the profile of the problem with politicians and add more support to the need for them to take action to change this situation.

If you haven't taken part in the e-action yet, please go to [http://www.mndassociation.org/get-involved/campaigning-influencing/general-election-campaign-2015/general-election-campaign-2015.htm?wbc\\_purpose=basic](http://www.mndassociation.org/get-involved/campaigning-influencing/general-election-campaign-2015/general-election-campaign-2015.htm?wbc_purpose=basic) and follow the simple steps to send a pre-prepared email to your MP and candidates. The more emails they receive, the more they will understand how important it is that people living with MND don't die without a voice. If you have experienced any problems getting access to communication support, please get in touch and let us know!



*Anita Sinclair—see article on facing page*

***Local support for local people***

## **Respiratory Services for Patients with Neurological Conditions**

***Anita Sinclair***

This is a one year project, jointly funded by the MNDA (in memory of Martin O'Shea) and the Wiltshire CCG, with the goal of setting up respiratory services for neurological patients in the Wiltshire community. The role also manages a caseload of MND patients with respiratory needs in the community setting.

In Wiltshire, patients access respiratory services in the three district general hospitals (GWH, Royal Bath Hospital, and Salisbury Foundation Hospital) and the three Tertiary Sleep/Ventilation Units, in Oxford, Bristol and Southampton. This complex set up poses a real challenge for community clinicians due to a lack of integrated respiratory pathways for treatment, the limited communication between health service providers, and variability in level of skills to handle respiratory concerns. Working to meet patients' needs and sustainability in the home setting is therefore extremely variable.

Having previous experience as an MND Practitioner in Gloucestershire, setting up the service in the Wiltshire community, an equally rural setting with a similar population number, allows me to grasp quickly how to navigate the system and transfer skills and practice to this new service.

To bring about sustainable change in this service, the role focuses in the following areas:

- ⇒ Set up robust integrated networks between professionals to ensure a seamless service for patients and their families.
- ⇒ Set up integrated respiratory pathways that ensure regular monitoring to allow early detection and optimise treatment options.
- ⇒ Promote an environment that encourages evidence-based practices using up to date treatment approaches.
- ⇒ Set up training packages suited to the skill mix of professions in the community.
- ⇒ Access to respiratory equipment for community clinicians for both diagnostic and treatment purposes.

Is this achievable in one year? Change in practice takes time, patience and perseverance. I very quickly realised the large scale of the task at hand. It also takes teamwork and knowledge transfer mechanisms, so I'm very grateful for the support of the committed steering group, with key representation from GWH, Wiltshire community and the MNDA.

I believe that implementing the above goals will allow patients a timely, informed choice in advance of deterioration, and feel privileged to be given the opportunity to focus in this critical yet highly specialised area. Having a readily available pathway will also allow patients a voice in the management of their condition and protect their autonomy. Finally, the presence of integrated respiratory services will help reduce crisis management and unnecessary admissions.

## 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 08457 626262**

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

**MNDA Volunteering Team  
01604 611681**

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

**Prospect Hospice 01793 813355**

**Dorothy House 01225 722988**

## 'Condemned to Silence' hits Parliament

On 27th January, our Campaign Contact, Heather, attended the MND All Party Parliamentary Group (APPG) round table to launch their research report into access to communication aids for people living with MND. Heather was joined at the event by other Campaign Contacts from around the country and the roundtable was hosted by Madeleine Moon MP, Chair of the APPG and whose husband was diagnosed with MND in 2010.

The report is available to read on the MNDA website <http://www.mndassociation.org/Resources/MNDA/Campaigns/Documents/appg-report-final.pdf>. There is also an Executive Summary at <http://www.mndassociation.org/Resources/MNDA/Campaigns/Documents/appg-executive-summary.pdf>

The whole day was extremely powerful in raising awareness of the need for change in the process of access to communication aids and to follow the event with a mention in Prime Minister's Questions was fantastic. As the General Election looms, it will be interesting to see what happens next for the APPG and the implementation of the report. What is for sure is that the profile of the needs of people living with MND has never been higher amongst politicians and there is a real opportunity now for change.

## Support for You

### What's On?

#### 19th February

Calne Support Meeting, Stainer Road

#### 5th March

Committee Meeting, Prospect Hospice, 7pm

#### 19th March

Swindon Support Meeting, The Lawns

#### 2nd April

Committee Meeting, Prospect Hospice, 7pm

#### 16th April

Calne Support Meeting, Stainer Road

#### 7th May

Committee Meeting, Prospect Hospice, 7pm

#### 21st May

Swindon Support Meeting, The Lawns

#### 4th June

Committee Meeting, Prospect Hospice, 7pm

The MNDA N Wilts Group is one of the Waitrose Community Matters (Green Tokens) beneficiaries for February at their Malmsbury store. If you shop there, be sure to drop!

The deadline for submission for the next issue of the Newsletter will be **6th April 2015**.

*Andrew Sargent*

email: [AndrewRSargent@gmail.com](mailto:AndrewRSargent@gmail.com)



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

Registered Charity No 294354