

# West Dorset Motor Neurone Disease Association Spring newsletter 2019

## Happy New Year to all our friends from West Dorset MNDA.

This is our latest news, recent activities and highlights from 2018 which we hope will be of interest to you.

# <u>Our chairman, Richard Sloan, was invited to Russia to meet and advise Russian colleagues on the treatment and care of MND patients.</u>

"Last October, I was fortunate to be invited back to Moscow to teach on MND to a group of enthusiastic healthcare professionals determined to improve things over there. The Russian medical system doesn't cater very well for MND but things are changing due to the efforts of similar groups in various parts of this vast country. They have strong links with local patient and family volunteers who raise money for education and support – much like happened in this country 40 years ago with the embryonic MNDA. It's humbling to be with people of such passion and enthusiasm. They are also trying to change the paternalistic relationship which exists between doctors and patients and nurses by learning about autonomy, teamwork and communication skills.

Moscow is a fascinating thriving modern city with plenty to explore but not very representative of much of the rest of the Russian Federation which still suffers from deprivation since the collapse of the Soviet system 30 years ago. Despite the well-publicised political differences between our two countries, the people are very friendly and welcoming. It's easy to fall into the trap of believing through the media that all Russians are antagonistic to Westerners because of the political rhetoric but it works the other way too. The previous time I went to Moscow, I visited a patient in one of the big apartment blocks and, after the joint consultation with the MND team, we were all invited next door to the dining room where all the best crockery and tea service was laid out for afternoon tea with home-baked blinis!

I've made some lovely friends over there and it's always wonderful experiencing different aspects of life and culture in foreign countries and being reminded that there are more similarities than differences between us as human beings."

#### Richard Sloan



Chairman Richard's visit to Moscow-included some sightseeing as well as meeting healthcare colleagues





Richard Sloan (left) with Russian colleagues

#### Tess's orchestra morning.

Our media officer, Tess, brought her orchestra along to the United Church Hall in Bridport to entertain members of the public who had dropped in for Saturday morning coffee and chat.

### **Spenstock rocks Weymouth Pavilion!**

The Bates family from Weymouth worked hard to present another Spenstock music event at the Pavilion in memory of Nicky's musician husband Spencer-a victim of MND. That event raised £875 for West Dorset MNDA. Watch out for news of the next SPENSTOCK to celebrate 40 years of the MND Association.

#### **Bridport celebrates MND Awareness Day**

In June last year, Bridport Town Hall clock was lit in orange to mark MNDA awareness month. A street collection was also held in Bucky Doo Square.

We hope to repeat this event in June 2019 with the support of Bridport Town Council.







#### Weymouth College held a day of information

In the summer of last year, 25 school students from throughout Dorset took part in an awareness and fundraising exercise for our Branch as part of the National Citizenship Scheme. Students from 15 -17 years old enrol on the Scheme to improve self-confidence, socialising skills and teamwork and have to pick a community-based project at the end of their course.

With support from the Branch, they visited Dave Scragg at Weldmar Hospice to learn from his experience of the illness and then embarked on organising a sponsored walk in fancy dress, a quiz night and sponsored bake-off – all over the course of a week!

They even made a video of their exploits which is posted on YouTube to publicise the activities of the MNDA and to pay tribute to Dave.

https://www.youtube.com/watch?feature=youtu.be&v=vTJGls9yWSs&app=desktop

Dave said, "It was a pleasure to talk with the young people and explain that, even though the illness is terminal, there's still plenty about life to enjoy. I loved their enthusiasm and it was wonderful to see their video and feel that I had, in some small way, inspired them to do this."

Through the sponsored events, the group raised the grand total of £550 towards Association funds – a fantastic achievement and a positive experience they will never forget.



#### Jane and Jerry's summer ramble around Colmer's Hill followed by a most delightful tea.....

The walk with cream tea, took place on August 17th, and we were lucky enough to have a glorious day for it. It was optional, you could just come for tea, but it made it easier for parking if people walked. We did offer lifts back to Symondsbury, if required. The walk was from Symondsbury up a green lane that runs along the ridge to Denhay Farm, above our house. We put signposts along the route and it took about 40 minutes to do, unless you got lost; and on arrival there was a cream tea with scones, home made jams and cakes. There was a steady trickle of people who came, to whom I am very thankful. We made about £200 for Motor Neurone Disease, which I felt had been worth the effort, and we will do it again this year, but maybe at the end of July next time.

Several intrepid people decided to make up a splinter group for the walk led by our Chairman, Richard. Sadly they got very lost deep in the Dorset countryside but thankfully were rescued by the search party sent out to find them! They were all in good spirits and had enjoyed their taste of adventure!

<u>September saw another walk</u>, which was organised by committee member Jenny. This took place along Weymouth seafront. The walk was wheelchair friendly and was enjoyed by people with MND, their families, friends and dogs! This lovely event raised over £2000!



#### Local landscape artist Frances Hatch opens her studio in aid of MNDA

She had to leave her home relatively quickly when she was bereaved of her husband, a clergyman, who died of MND in May 2018. She moved her home and her studio to Weymouth to start a new life in a new town.

Frances opened her studio for the first time to friends and clients recently, and she decided to offer selected works as donations towards the work of West Dorset MNDA, raising.....

Frances will again be opening her studio on February 28<sup>th</sup> until March 3<sup>rd</sup>, and if you would like to enquire about opportunities to see her work, visit <u>info@franceshatch.co.uk</u> <u>www.franceshatch.co.uk</u> or to visit by appointment, telephone 01305 896162 or 07946903930

#### **Great news!! Dorset County Council has adopted the MNDA Charter.**

This will greatly benefit all people living with MND in Dorset and their carers as well. A referral to council services will be prioritised for people with MND to ensure prompt response to needs.



From left to right, Councillor Richard Biggs, Steve Bates, Mary Bates, Councillor David Harris

<u>The annual Christmas Tree Festival</u> at Bridport United Church was another big success, raising £250 for our local branch and delighting local adults and children.



<u>Wessex Morris Men</u> performed around North Dorset during December and we are grateful to them for raising £300 for West Dorset MNDA.

Our year ended with a special <u>Christmas lunchtime meeting at Sherborne Garden Centre</u>-a happy occasion for all who attended. Our relaxed Garden Centre meetings will resume in March 2019 and we look forward to welcoming friends old and new.



## STOP PRESS! A new project for 2019! Calling all carers of people with MND!

We have two dates for your diaries. On Thursday 7<sup>th</sup> March and Friday 28<sup>th</sup> June 2019 Carers Support Days have been arranged. These will be held in the Day Centre at Joseph Weld Hospice. More information will be available from your Association Visitors in due course.

<u>This year is the 40<sup>th</sup> Anniversary of the MNDA</u>. With this in mind we are hoping to stage a special event to mark the occasion-any ideas or help for this proposal will be gratefully received.

<u>HELP PLEASE!</u> We are keen to develop the work we do in West Dorset to help patients and their families who are affected by MND. We are always grateful for any help in raising money and raising awareness of this disease. Help with the administration and organisation of meetings and events would be invaluable. If you have any skills that would be of benefit to our small group we would love to hear from you.

If you would like to receive any further information regarding volunteering or support please contact the secretary, Jane Scott

janeshawscott@aol.com