

NEWSLETTER

South Yorkshire Branch Autumn 2013



'Sally Light, MNDA Chief Executive at Sheffield's Botanical Gardens'

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mnda

motor neurone disease
association
Registered Charity No. 294354

Welcome to the Autumn edition of the MNDA South Yorkshire Branch newsletter.



In this edition we have some encouraging stories from Doncaster, Sheffield and beyond, as well as fundraising news and updates on future events and meetings.

All members of the MNDA SY committee have been pleased to see so much national awareness-raising for MND on TV in recent weeks and months. Alan Titchmarsh and his team have redesigned two gardens for MND patients on ITV's Love Your Garden, and the BBC's DIY SOS team converted an entire house for a man with MND and his family in Enfield. If you have access to the internet you should be able to find these programmes by Googling their titles alongside 'MND'.

Do you have a story you'd like to share? Would you like to pay homage to your carer? Have you found that having a pet has really helped you, or have you found a way to overcome a particular obstacle? We love to hear your stories so please send them to fran@franhallwriting.com.

Thank you once again to Westfield Health for their donations towards the newsletter.

Fran Hall

Chairman's Report

It is with considerable pleasure that I am able to report that your Association has once again been very busy during the summer period: Julie Drakeley eventually managed to get her 80s night off the ground having been forced to cancel in March due to the snow; another successful Open Garden at Owl End was held - courtesy of Sue and Roger Thompson; we had a glorious evening in Sheffield's Botanical Gardens with special guest Sally Light, the new Chief Executive; and a memorable Awareness Day on June 21, to mention just a few events.

Of course we now need to maintain the pace and continue to raise awareness of MND and seek innovative ways of raising much needed funds throughout our area. It was very refreshing to listen to the Association's new Chief Executive, Sally Light (see front cover) and we are perhaps already witnessing a fresh and healthy relationship developing between Branches and National Office. A Regional Meeting has been set up in October with the aim of National Office taking on board the concerns and aspirations of the Branches and we are also in the process of arranging a visit by Alun Owen, the Chair Elect of the Board of Trustees.

Mel



Our mascot, Mo-Lecule the Meerkat

Treasurer's Report

We have just passed the half way mark of the financial year. We had an amazing start to the previous financial year so it was unlikely that we would come close to it this year, and that has proved to be the case, with income for the first six months being £17,508 compared with £28,271 last year. The income from the half marathon and fun run provided a significant contribution. The South Yorkshire Branch income is still sufficient to meet all the demands of people living with MND in our area. Money spent on care and support for the first six months amounted to £12,388.

Paul

Barnsley Open Meeting

September 11th will mark another important step for the Branch as we hold our first Barnsley Branch Open Meeting.

As a complete change we have decided to hold the event at the Pot House Hamlet Restaurant in Silkstone. Niki, the proprietor, is very supportive and the Hamlet provides a pleasant venue with adjacent garden centre and a mixture of other units.

Although the concept of the extra Open Meeting on the calendar is to offer the people of Barnsley and surrounding area an easier trip to attend meetings, anyone is welcome to attend.

See page 7 for more details.

I Am Breathing



June 21st was designated Global Motor Neurone Disease Awareness Day and to mark this very special day the services of the Showroom Cinema in Sheffield were secured and a memorable screening of the film I Am Breathing took place.

We were delighted to be able to welcome over 100 viewers including our local MP Paul Blomfield, the Mayors of Barnsley and Rotherham, local MEP Linda McAvan and many health care professionals and students. The opportunity was also taken to use this gathering of the distinguished to collect many MND Charter signatures.

SITrAN (Sheffield Institute for Translational Neuroscience) also attracted over 100 people to their showing of I Am Breathing at the research institute on Monday 24th June. Scientists and researchers were able to sign the charter.

In addition to this, members of the Sheffield MND Research Advisory Group met with Sir Andrew Cash, Chief Executive of Sheffield Teaching Hospitals, earlier this month where he also signed the MND Charter.

Your Stories



Left: The Flying Scotsman

Below: Merlin



These intricate steam trains have been drawn by Pete Cutts, a former colliery worker from Doncaster.

A keen artist all his life, Pete has braved MND for 22 years and feared the disease would spell the end of his beloved hobby. He tells us about his life before diagnosis and beyond:

"I've lived in Mexborough my whole life and worked in the Survey Department at Cadeby Colliery for many years. When the colliery closed in 1987 my wife Brenda and I bought a fish and chip shop which we really enjoyed running. After we sold this we bought a café in Mexborough town centre. Unfortunately though, after being diagnosed with MND in 1991, I had to retire the following year.

Over the years my hands became more and more unsteady and my speech is now difficult to understand."

Good train-ing

Attending his local day centre has been Pete's saving grace, as it was there that he learnt to use a computer. "I've been attending the day centre now once a week for about ten years," says Pete.

"After learning the basics I bought my own computer so I could keep in touch with my grandchildren via email. Once I became more proficient on the computer I then taught myself to draw and paint locomotives on the computer's art programme, Microsoft Paint.

I've been confined to my wheelchair for over 20 years now so being able to resurrect my hobby has been a real lifeline for me."

Day Centre Success

It can take a lot of courage to visit a day centre for the first time but one Doncaster woman wishes she had taken the plunge a lot earlier.



Maureen Needham tells us her story.

My name is Maureen and I'm 57 years old. I have a daughter and two grandchildren. In June 2012 I was told that I had Motor Neurone Disease. It took me a while to accept the news. I can't speak and I'm fed through a PEG tube in my stomach.

The MND nurse who visits me at home asked if I wanted to go to my local hospice day centre, and for a while I declined, but she encouraged me so much that in the end I went along.

The staff and other members were all so friendly and there is a nurse who helps me. After I'd been a few times I decided I wanted to make people smile so I started to dress up. I've always loved shopping, for shoes particularly, so it was right up my street. Some of the costumes I've dressed up in are a black and purple wig and red nose for

Comic Relief, a cowgirl and a builder's outfit. I'm glad to say that everyone laughed and I'm always on the lookout for new costume ideas.

By going to the day centre I've been able to meet other people, do art work, get my hair cut, have my nails done and I've even had a massage. I look forward to going every Tuesday now.

Garden Opening at Owl End

The Open Garden weekend raised just over £1,000 for the South Yorkshire MNDA, despite some cool and at times wet weather. The refreshments tent overflowed with cakes, and it was really good to see how it provided a meeting (and resting!) place for visitors. The money raised here, together with all the proceeds from sales of plants goes to the MND Association, while the garden entry money goes to the National Garden Scheme charities.

Thank you to everyone who helped on the day and to the staff at SITrAN particularly for your support and wonderful cakes!



The Toughest Footrace on Earth



A challenge means different things to different people, as anyone living with MND knows. However the incredible fundraising challenges that some supporters of the South Yorkshire Branch undertake leave many of us speechless and the Marathon des Sables (MdS) is probably up there at the “madness” level.

Most people who are fit enough to complete a half or full marathon in this country couldn't even contemplate this gruelling adventure. The toughest footrace on earth covers 150 miles and takes place through a formidable landscape in one of the world's most inhospitable climates ... the Sahara Desert!

Paul Minns' account of his race:

The 28th MdS

“In April this year I set off for Morocco to run the 28th Marathon des Sables sharing Tent 142 with Graeme, Richard, Stuart, Denise, Paul, Tarique and Simon throughout the week. The MdS is a 6 stage race over 150 miles across the Sahara Desert and takes you across salt plains, mountains, dried river beds and the inevitable sand dunes!

The terrain was tough this year and involved crossing 3 Jebels (mountains) on day 2 as well as 14km of monster sand dunes during the notoriously long 50 mile 4th day. As if this wasn't bad enough the heat on day 3 soared and a temperature of 54 degrees was recorded. This was repeated the following day and caused quite a few to seek medical attention which involved being hooked up to a saline drip (and a time penalty). I was lucky to come away without a single blister but the vast majority had to visit Doc Trotter's medical tent at some time to have their feet ‘seen to’ which involved a pretty crude operation using a scalpel and iodine to remove the dead skin and prevent infection. The tent was like a scene from M*A*S*H for anyone old enough to remember!

The MdS is a race but the vast majority of competitors are simply there to challenge themselves. I met some truly inspiring people from all around the globe including Mohamed from Morocco who took part on a prosthetic leg, a Japanese guy who ran every stage dressed as a cow, to a team of French firefighters who carried a disabled child in a purpose built chariot across each stage.

The MdS was an amazing experience and I'm glad I used the opportunity to raise some money for the South Yorkshire MNDA.

The Branch would like to thank Paul for this modest account of his amazing adventure and also for donating over £1200 raised from the challenge.

The Motor Neurone Disease Association

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Branch Meetings in Doncaster, Rotherham and Sheffield, 2013/14

2pm start unless otherwise indicated

Sheffield

Salvation Army Citadel, Psalter Lane,
Sheffield S11 8YN

Tuesday 15th October

Tuesday 10th October

Rotherham

United Reform Church,
Stag Roundabout, Wickersley,
Rotherham S60 4JN

Monday 2nd September

Monday 2nd December

Doncaster

Linney Centre, Weston Road
Doncaster DN4 8NF

Thursday 7th November

Barnsley

The Potting Shed, Pot House Hamlet,
Barnsley Road, Silkstone, S75 4JU

Wednesday 11th September

Anyone needing further information on
Branch meetings, or assistance in getting
to a meeting (including funding for taxis)
please contact a Committee member.

Winthrop Gardens Visit

As detailed in the Summer newsletter, we are having an Open Meeting at Winthrop Gardens, Wickersley, near Rotherham on Wednesday September 18th. We will meet at 4pm for a wander around the gardens, followed by refreshments (in the newly-converted sewage works!). Members have enjoyed this visit in the past, and we hope that as many as possible from across South Yorkshire will be able to join us for an informal meeting – we will finish by 6pm.

**Winthrop Park,
Second Lane (Off Newhall Avenue)
Wickersley, Rotherham
South Yorkshire, S66 1EE
Tel: 01709 – 709335**

Could everyone who plans to come let Sue Thompson know, as the owners of Winthrop need an idea of numbers for catering purposes, and also any information about dietary requirements.

**Sue Thompson
0114 2350830
owlend@gmail.com**

Wheelchair accessible car for sale

Renault Kangoo 5 door estate with Gowrings Mobility wheelchair conversion, 2006.

1.2 Authentique (petrol) blue.

21,000 miles.

Very good condition.

5 speed manual.

MOT - May 2014.

Full Service History.

£4250.

Call **07794 480110** for more details.

Past Carers' Meetings

The next Past Carers' meetings will be on Sunday October 13th and December 8th at 2pm in the Millennium Gallery Cafe. Please call Olga for more information: **0114 236 1179/262 0237**

olgabannister@talktalk.net