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mnda motor neurone disease association

Reading and West Berkshire

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News Letter

Our Unsung Heroes

These of course are people who are carers of those living with MND.

Thirteen of them gathered one Friday lunchtime at the Holiday Inn to spend the afternoon together. After a wonderful lunch delegates enjoyed three topics during the afternoon.



Margaret Moss (Branch Chair), Jane Owen (Clinical Specialist Nurse), Anita Balmer (OT), Rachel White (OT), Bridget Foden (AV) and Jane Iles (former carer)

Two occupational therapists (OTs) from Wokingham covered many types of equipment and services which would be available to help people with MND and therefore would help the carers. The presentation covered a variety of situations which might be encountered by a family.

This session was followed by a former carer telling her story; the story of caring for her husband during their journey with MND. She said that she had encountered many situations commonly met in daily life and made practical suggestions that those present might find useful.

The third session was delivered by the clinical specialist nurse for rare and complex diseases who talked about her experiences at clinic and in the family home and how she could help. Dealing with several rare neurological diseases means that she cannot always do whatever's best and timely.

It was good to see so many people helping each other, learning from each other and supporting each other in all sorts of ways. Many questions were asked by the carers during all three sessions and so provided a useful forum for sharing the experience and knowledge they all have.

Delegates were very helpful with filling in all the required forms for the funder; the day had been made possible by generous funding, for which we are very grateful, from the National Health Service Partnership Development Fund. In the recent past this fund also enabled the branch to run a one day training course for GPs and health and social care professionals as well as a whole day for carers.

As ever the support and help from committee members in organising the day and in being there on the day was instrumental in it going so smoothly.

The day ended with tea and cookies for all. The speakers were presented with small gifts in way of thanks for taking part.

But overall our thanks go to the carers themselves - they are our Unsung Heros!

Margaret Moss

Registered Charity No 294354

Creating MND in a dish

A leading researcher has told of his pioneering stem cell work creating MND in a dish which it is hoped will lead to future drug treatments.

For the first time revolutionary technology is being used to study early changes in the disease thanks to stem cell and brain tissue donations from patients at the Oxford MND Care and Research Centre.

Dr Jakub Scaber, Lady Edith Wolfson Clinical Research Fellow, works in Professor Kevin Talbot's laboratory on a programme set up in 2007 to attract and train the brightest and best clinicians to MND research.

He was invited to speak at the AGM in March about his work which is partly funded by £45,000 from the Sheila Hamblin Legacy bequeathed to the branch last year.

Afterwards Dr Scaber wrote:"Thank you so much for inviting me – it was a pleasure to be able to talk to everyone, and to be able to give back a little for the lots that I have received.



Lin Jenkins receives her award from Branch Chair Margaret Moss

"I want to thank you and the Berkshire branch for helping to fund my fellowship and studies, and yesterday's meeting was an inspiration and a real encouragement to continue the work I do."

Dr Scaber has been focusing his work on a familial gene mutation which affects just five per cent of people affected by MND. For the other 95 per cent of people living with MND there is an unknown trigger causing the disease. By creating human motor development in a dish scientists can replicate features of MND, identify early changes to help unravel the mystery and build up drug testing.

Other highlights at the AGM were:

· a report from treasurer Ed Gryglaszewski announcing "another good year" with receipts of just under £63,000. Out of that £36,000 will be transferred to national office leaving a general fund of about £20,000 to start the new year;

· tireless fundraiser Lin Jenkins received her award for five years long service and

· former rare conditions specialist nurse Carol Allen joined the committee and will advise on certain benefits

Jane Gilbert

George tees up a golf challenge

Keen golfer George Harrison is teeing up to play four rounds at four different courses - all in one day.

His massive 72-hole challenge on June 21st is in memory of beloved step-dad Ronald Morrison, from Hungerford, who died of MND last May.

George, from Manton, Wiltshire, explained: "I want to raise money to help the MND Association find a cure so that in future other sufferers and their families have the hope my family didn't have after Ronald was diagnosed."

His first two rounds are at Stockbridge where he is due to play the Old Leckford and the New Leckford courses. Then on to the Newbury and Crookham Golf Club with the last round of the day at Deanwood near Newbury where George's wife Carol and mum Betty will be cheering him on.

To support George's fundraising for research into MND visit:
www.justgiving.com/inmemoryofronaldmorrison

Jane Gilbert



Ronald Morrison enjoying a barge trip



CONTENTS

1 Our Unsung Heroes

2 Creating MND in a dish
George tees up a golf challenge

3 Spring garden sale
Charity Night in aid of MND

4 Generous gift from telecomms staff
Fabulous fundraisers Meredith and Stuart

5 Three cheers for our amazing runners

6 Coffee, cake and creative vibes
Unwanted items to dispose of?
Remap

7 Running is the best tonic for carer Viv!
Let's Rock 'n' Ale

8 Do you Facebook?
Arjo Huntleigh lifting hoists available

9 Safari after dark
Who needs favours?
Beenham charity sale

10 Letters, What's on and Items for sale

Spring garden sale

Our Annual Spring Garden Sale was on Friday 29th and Sat 30th April.

We set up our gazebo on the front drive, and proceeded to fill the entire front drive and garden with a large selection of stock for sale. Living on a main road, which is also a bus route - and with local schools nearby – helps, as we put a large banner on the front hedge to advertise.

We had simply crowds of people dropping in, and it was lovely to talk to them. Many have been touched by MND, and they were so grateful for what we were doing. Many left donations of money, or other items to sell. We made a magnificent profit of £333 over the 2 days but the heartfelt comments counted for so much as well.

Thanks to everyone who supported us.

Lin Jenkins

Don't forget that you can recycle used printer cartridges and old mobile phones to raise money for the MND Association.

Get a supply of envelopes by calling 01604 611888 or email corporate@mndassociation.org.

Just put your phone or cartridge in an envelope and pop it in the post - no stamp required!

If you would like to receive newsletters by email please contact Val Pearson: Valerie.a.pearson@btinternet.com

Please also contact Val if you know of anyone else who would like to receive a copy of the newsletter by post or email

Generous gift from telecomms staff

Generous staff at CTIL have given a £1595 boost to the vital work of the Motor Neurone Disease Association.

The donation is thanks to Charlie Grice, a governance manager at the Theale-based telecommunications infrastructure company, who nominated the charity close to her heart.

Charlie, aged 26, urged her colleagues to give the proceeds from a bumper raffle to help people in Berkshire living with MND.

She said: "It's an important charity to my family because of my uncle Ian. My mum is his primary carer and we get a lot of support from the Association. I am really pleased that it was chosen."

Sadly, since the presentation in February, Charlie's uncle, Ian Hill, of Newbury, has recently lost his long hard battle with MND.

Managing director Malcolm Collins presented the cheque to Jane Gilbert, branch publicity officer.

Jane thanked CTIL staff for their amazing generosity and said the donation would make a real difference to families affected by MND.

"We step in to fill the gaps left by the statutory services and it is important that we can respond quickly as MND is a progressive condition," she explained. "People living with MND do not have time to wait months for support and equipment."

The branch decided to spend the money on the rental of a stairlift for a disabled man unable to get out of his flat , a course of aromatherapy and massage for a woman living with the debilitating effects of MND and a grant for a carer to take a vitally needed break.



Charlie Grice (centre) with Jane Gilbert and CTIL's Debra Conner

CTIL acquisition specialist Stuart Cheslett also teamed up with Charlie to raise funds for the Association by running the Reading Half Marathon on April 3rd. See story on Page 5. To donate:

http://www.justgiving.com/Stuart-Cheslett

Jane Gilbert

Fabulous fundraisers Meredith and Stuart

See story on page 5



Meredith Miller's Brighton Marathon Run (above)

Stuart Cheslett (right)



Three cheers for our amazing runners

A trio of amazing runners has helped to get this year's branch fundraising off to a flying start.

Stuart Cheslett, Kirsten Wood and Meredith Miller all proudly wore the MND Association running vest at the Vitality Reading Half Marathon on April 3rd.

Between them they have raised more than £3,000 from their inspirational efforts and helped to highlight the vital work of the Association.

For busy working mum Meredith it was a warm-up for the more gruelling Brighton Marathon which followed a few weeks later.

Meredith, aged 40, fitted her training around her job as a tax consultant and looking after her young family at home in Caversham which meant a lot of early starts.
She was inspired by her "amazing" dad Bill Potts who died from MND two years ago just five months after diagnosis.

"My dad was a US marine in his youth and told me he used to run marathons in full military gear, said Meredith. "I always said I'd never run a marathon but thought I'd give it a go this year. It was great and I managed to finish with a time of five hours six minutes."

Celebrity Zoe Ball, who opened the Brighton Marathon on behalf of the Association cheered on our runners and gave Meredith a shout out at mile 23.

Meredith, who was running with her friend Judy, collected more than £1500 in sponsorship for completing the challenge.

She added: "I'm really pleased to be able to raise some money for the charity. I've put in for a donation from my employer again this year so hoping to be able to add that too!"

Reading runner Stuart Cheslett knew little of the difficulties faced by people living with MND until one day when talking to work colleague Charlie Grice who persuaded him to run in aid of the branch. They struck a deal – Charlie would rally the sponsors and Stuart would do the running. Their hard work paid off and together they raised £1,112.

Stuart, aged 55, an acquisition specialist at Theale-based CTIL, said:" When I decided to do this event I decided to take my time in deciding who I'd like to do it for and I'm glad I did because while there are many worthy causes I felt the MND Association's Reading and West Berks Branch stood out."

Sadly, Charlie's beloved uncle, Ian Hill, died, aged 63, on April 19th at the Argyles Nursing Home in Newbury after a long hard battle with MND.

Thirty-six-year-old Kirsten Wood, from Burghfield, chose to run her first half marathon for the MND Association because "they had done so much for my dad".

Her dad, Ronnie Slater, from Tilehurst, who is living with MND, cheered her on around the seven mile mark and was waiting proudly at the finish with his wife Jane.

Kirsten, an internal accounts manager with Microsoft, said afterwards: "It went well. I managed to do it in 2hr15m which was 5 minutes quicker than I was expecting! This was my first half marathon and it was done with this great cause motivating me all the way!
"I am sincerely grateful for the way the MND Association have been looking after my Dad! We would be lost without your support. Helping to raise funds is really the least I could do to say thank you!

"Please pass on my gratitude to everyone at the MND Association. You are all amazing and are doing such a wonderful job helping improve people's lives!"

Kirsten, raised £636 from her running efforts and husband Greg Wood, a self confessed big meat eater, donated £538 from his Vegetarian January.

He said: "The MND Association have been a great help to my father in law and all around him over the last couple of years. Motor Neurone Disease is therefore a cause very close to me and my family's heart so I would like to sacrifice my wholehearted love of meat for January 2016 to help raise funds and awareness".

Jane Gilbert



Kirsten and Greg Wood with dad Ronnie Slater

Coffee, cake and creative vibes



Jane Gilbert, Margaret Moss, Val Pearson and Paddy Lunn



Sue Lunn at the Art Cafe

Our volunteers served up tea, coffee and delicious home-made cakes at Whitchurch-on-Thames' new community Art Cafe.

Every Saturday morning the doors of The Old Rectory Stables are opened from 10-12.30 to bring in people who enjoy art and chatting with friends to raise money for good causes.

The branch booked a slot for the first time on April 9th and collected £228 for the MND Association from selling refreshments, cards and raffle tickets.

Organiser Gill Williamson came up with the idea after visiting similar Art Cafe projects and teamed up with two village churches which use the premises as a meeting hall.

"I am thrilled how it has turned out," said Gill, who paints in mixed media and graduated in sculpture. "It has been a great collaboration between the church, community, charities, and artists who exhibit their work. We started in November and have raised £2,700 for charities so far."

The MND Association hopes to pop up again in the tranquil Thames-side village in the Summer – come and join us!

Jane Gilbert



Remap

'Those of you who attended the Carers' Conference on 6th November 2014 will remember the free service that Remap offers to make special aids to help with everyday tasks and hobbies.

If you think you would benefit from an aid but cannot find anyone who supplies it, then Remap will make it for you.

Just send your request to Robert Monk at BerksRemap@gmail.com.

Some examples of jobs Remap has undertaken include

- Constructed a device that allowed the user to raise or lower his reclining chair simply by putting his feet on some special strips.
- Fitted an extended handle to an electric blanket control to simplify operation .

Get further information about these and other projects at :

http://remaponline.org.uk/remapedia/category/remap-projects/

Running is the best tonic for carer Viv!

Inspirational Viv Wilkes finds running the best tonic to combat several serious health conditions that she has to cope with.

Viv, who has Parkinson's and epilepsy, lost her own carer when husband Colin, aged 65, was diagnosed with MND just before Christmas last year.

The couple, from Thatcham, discovered the shattering news after a chance meeting with Viv's neurologist in Dorset when Colin was advised to seek medical advice for himself.

Despite this double blow the plucky couple are determined to make the best of their life together.

"We get through this with a sense of humour," declared Viv who regularly does six to seven mile runs on a Sunday morning and would run every day if she could.

She caught the bug after running the Race for Life about 16 years ago and now has two London Marathons under her belt – the second completed a year after she was diagnosed with Parkinson's.

Viv, now aged 64, told other runners at the time: "I have got Parkinson's, I am not running for Parkinson's!"

The retired West Berkshire benefits assessor goes running in all weather with her friend Geraldine and Thatcham voluntary group Team Spirit which supports runners.

"You have got to think that you can do it," she explained. "I call it a free drug – it makes me feel heaps better.

"I completed the Bramley Ten on 14th Feb in 1.47 which was slower than the 1.38 for last year, but this year I ran on my own most of the way and I had to stop for 'a call of nature' after two miles. Looking for a suitable place on a set running route is not easy to find! (Too much information I know but I feel better explaining the slower time taken this year). "



Viv expects the Bramley Run may be her last event as she will be spending more time looking after Colin as his condition progresses.

"I have lost my carer now and we will try and keep each other upbeat," she added.

Jane Gilbert

Let's Rock 'n' Ale

Caversham Rock 'n' Ale Festival is back and once again supporting people living with MND.

The beer and beats will be flowing from 6.30pm on Saturday, June 18th, at St Anne's School Playing Fields.

Rock 'n' Ale was first run in 2013 as a one-off tribute event raising money for the MND Association in memory of popular Caversham teacher Angela Fung.

Mum-of-four Mrs Fung, died, aged 53, after a brave battle with the disease and her amazing friends have kept up their good work for the charity.

They give their time to run and manage the event free of charge as do all the bands who play on the night and it now attracts a wide range of music fans from Caversham, Reading and the surrounding areas.

One of the organisers Mike Ryan said It is first and foremost a community event and is attended by people of all ages.

"The Parish have again agreed to donate half the profits to the Association and I understand from one of the bands that are playing that one of their mothers has just been diagnosed with the disease, " he explained.

"Last year there were just under 400 people which, given the weather, we were pleased with and represented quite an increase on the previous year's event so we are hoping to beat that this year.

" if there are any people living with the disease that might enjoy the evening we would be very happy to let them and their carer have a couple of free tickets."

To buy tickets call Pack & Send, one of the sponsors, during office hours on 0118 958 4498 or visit We Got Tickets www.wegottickets.com/event/355687.

For more details, including the line-up, visit www.rocknale.co.uk.

Jane Gilbert

Do you Facebook?

What's to say about Facebook, you either love it or hate it, but it's here to stay for the time being until some other bright spark designs a new and more favourable means of communication.

At Reading and West Berkshire MND Association we felt the need to get more involved with a social media website as this appears to be the way forward.

With the help of our branch supporter Andrew Wall, we managed to develop and set up our branch Facebook page. At first we stumbled along trying to get to grips with the social networking site, and we are still making progress in some areas and enjoying each new achievement.

Our Facebook page has been online for over 12 months and is well supported by so many people. It's a great way of raising awareness of Motor Neurone Disease and for all those amazing people who constantly give their time to support the branch with their fundraising efforts. Goodness me, where would we be without you? Thank you everyone!

Please continue to follow us on Facebook; **MND Association Reading & West Berkshire**

If you get the chance to look at our Facebook page please support us by clicking 'Like'. Share with your friends to help spread awareness.

- twitter.com/MND_RWB with over 400 followers, we're inching closer towards the 1,000 mark!

Mary Dodds

Two Arjo Huntleigh lifting hoists available

Maximum lifting capacity - 30 stone

Track lengths for the hoists:

3 x 9' 6" lengths and one 5' 3" length.

One 9' 6" length can be used as an 'over bed' hoist.

Two 9' 6" lengths and the 5' 3" length can be made into an 'H' frame - all fixings available. Instructions for fixing and using are also available.

All the above are as new as they were not used more than a few times,

It would be lovely if someone else could have the benefit of using them.

No money is wanted for these items but as the Branch made a contribution to help pay for them, a donation to the Branch would be appreciated.

In the first instance please contact Joanna Knott on 0118 984 4495 or by email tjmknott@talk21.com for more information.



Safari after dark

Samantha Grice and her friends have been doing what university students do best – partying – and they've raised £300 for a good cause while having fun.

Their ingenious fundraiser was a bar crawl dressed as animals around Bedford Place, Southampton, on April 30th which was aptly named Safari after Dark.

Samantha, from Newbury, was determined to go ahead and raise funds for the branch in memory of her uncle Ian Hill who died from MND just 11 days earlier.

She said: " I want to raise as much money as possible for my home branch of the MND Association as you have looked after my uncle so well. It truly has meant the world to me and my family. Thank you once again."

Ian, aged 63, was a big music fan and inspired his family to run various fund raising events including a night of rock and roll in his honour. Another niece, musician Sophie Hill staged the wonderful tribute for Ian who she dubbed Mr Brightside for the way he coped with living with MND.

Jane Gilbert



Who needs favours?

When Charlie Grice married Daniel Scaplehorn on Saturday 7th May, Charlie's cousin, Sophie Hill, designed these beautiful wedding favours for each guest.

The wording on the card reads:

Thank you for being a part of our special day.

In lieu of traditional wedding favours we have made a donation to

Motor Neurone Disease Association

We feel the best gift we can give is the gift of helping others, in honour of Charlie's uncle Ian, the bravest man we know

Beenham charity sale

We held our "annual" sale on Saturday 19th March. We had a fleet of 9 cars and vans to take all the stock from the storage area to the venue. In hindsight perhaps we took too much. We ended up with an army of helpers, and I can't thank them enough, for the help and support.

We had quite a reasonable footfall through the door, with many people prepared to rummage through everything, even the unpacked boxes.

Everything that was left then had to be transported back to our storage area. We did not make quite as much money this year, with total profit of £242.00, but every little helps.

However, it was a lovely networking opportunity. We met several families who have been touched by MND, and it is always nice to be able to chat with them. Two people from the village delivered more stock – including one couple who used to knit and sew children's clothes for another charity. They are no longer able to do this, due to health issues, so they were happy to hand over their remaining stock to us!

Our "workforce" was made up of family, friends, committee members and other friends from the branch. A thoroughly enjoyable day, and a HUGE thank you to them all.

Lin Jenkins

Thank you Holiday Inn Reading West, Bath Road, Padworth and Kall Kwik Printers, Reading for your ongoing support.

Letters

My husband and I should like to thank MND Association for funding the installation and six month rental of a stair lift. We sincerely thank you for authorising, so quickly, the Support Grant for this.

Barrie had been finding it difficult to negotiate the stairs to our first floor flat for some time.We thought that whatever condition was making it difficulot for him to walk could be cured by surgery or drugs so it was a great shock to both of us when he was diagnosed with MND on December 14th 2015.

The recommended stair lift company ATS was brilliant and came immediately to assess the work. They also rearranged their work schedule so that the lift was fitted on Christmas Eve. Thanks to the swift MND Association grant we were able to visit friends for lunch on Christmas Day and it has made a tremondous difference to both of our lives ever since.

Once again thank you so much for your prompt decision.

Yours sincerely

Jan Hicks

Mrs Jan Hicks

"I love receiving the branch newsletter. I always know from the envelope when it comes through the door what's in it. I make myself a cup of coffee and sit and read every page. It's so beautifully written, thank you for sending it to me."

Audrey Corcoran

What's On

Fawley Hill Vintage Steam Event Friday 20 - Sunday 22 May

Held in the grounds of Lord & Lady McAlpine at Fawley Hill, near Henley. Come along and join in the fun - look out for the bright orange MND Association gazebo. This will be an action packed event, with the addition of a Musical Extravaganza on the Friday evening. All monies raised from the Musical Extravanganza will be donated to the MND Association. See http://www.fawleyhill.co.uk/ for more details.

Sale at Southcote Community Hall, Coronation Square, Southcote Saturday 28 May

Jenkins Family Mammoth Sale from 10.00 - 12.00. We hope that a large number of people will be able to attend.

Chapel Row Fayre, Bucklebury Sat 27th August

This is a lovely event, held on the village green, next to The Bladebone.
All of the profits are shared between the MND Association and 3 other charities.

ITEMS FOR SALE

A large selection of folding garden/picnic chairs, in various colours (in cases). £3.00 each. Also a selection of camping and keep fit items. Contact Lin at rlp.jenkins@tiscali.co.uk or 0118 9412738.

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