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mnda motor neurone disease association

Reading and West Berkshire

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News Letter

Sales Manager uses eyes to communicate as he fights MND



A Berkshire sales manager who is only able to move his eyes refuses to let motor neurone disease stop him from working.

Steve Dimond from Newbury, who was diagnosed in August 2016, is determined to defy the cruel condition and continues to offer ideas on how to move his company forward.

Thanks to eye-gaze technology the brave 55-year-old dad is able to keep working for DMT Development Systems (UK) Limited in Bracknell.

His colleague at DMT, Kelly Boyson from Wokingham, says: "Every Monday we have a management meeting and Steve logs in via Skype. He comes back with ideas on how to move the company forward by email.

"He still works for us. I don't know how many people would do that when they are at that point in their life."

Steve uses an eye-operated communication and control system that empowers people with disabilities to communicate and interact with the world.

It involves a camera attached to his tablet which tracks the movement of his eyes. When he looks at a specific item, it allows him to select it and action it, whether it is a letter on a keyboard or launching an app. The system can also speak the selected words using his own voice that he recorded as his illness started to take hold.

He explained: "There's a camera attached to my tablet which tracks the movement of my eyes and knows what I'm looking at.

"Predictive text helps speed things up significantly."

Steve's wife Karen, 50, is now his full-time carer and recalls how the disease 'came from nowhere'.

She said it came completely out of the blue: "You can be absolutely fine one day and your world comes crashing down the next."

Karen says losing the use of his legs and arms has been particularly 'devastating' for him as Steve was a keen runner. He had previously run the London Marathon three times, raising money for Alzheimer's Society and Prostate Cancer charities.

"His best time was 3:23 so he wasn't a slow runner either," she said. But it was when Steve was training for a half-marathon in Reading in early 2016 when he noticed his times were dropping off.

Initially, Steve and Karen attributed it to his new job and spending more time in his car. Then after flagging it to his GP he was referred to a neurologist in Reading who suspected a collapsed disc and sent him for an MRI. When the scan came back negative and further symptoms developed it was diagnosed as MND – a progressive neurological condition that is life-limiting and has no known cure.

As the disease tightened its grip Steve's mobility worsened and he can no longer move his upper and lower limbs. He has now lost his ability to speak and eat and in February last year had a gastrostomy tube fitted meaning he receives all fluid and nutrition directly into his stomach.

Karen says this was one of the hardest parts: "We always used to love our food. Simple things like going for coffee or dinner you can't do anymore and you take it for granted till you haven't got it."

Steve has to contend with constantly changing symptoms as the disease relentlessly destroys more muscle groups but he has managed to retain his sense of humour.

Karen said the company had helped her husband battle on as his body shut down.

"He is one of the most positive people I have ever met," she said.

"His company have been absolutely fantastic.

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Sales Manager uses eyes to communicate - continued from front page

"They treat him exactly as they used to. A lot of people see he is in a wheelchair and don't realise that he is mentally all there.

"Before he had it I really did not know anything about the disease. It can affect anybody. "

See Page 4 to read about the fabulous fundraising by Steve's colleagues in aid of MND Association Reading and West Berkshire branch.

They have also posted a video on YouTube for the charity's ***Silence Speaks*** campaign - see https://youtu.be/JOLk1-n0-LQ .

To donate please visit:

https://www.justgiving.com/fundraising/dmt-mnd

Jane Gilbert



Picture (right) shows Steve and wife Karen at their home near Newbury

Billy is 'Pet of the week'



Bob and Billy featured in the Newbury Weekly News for Pet of the Week on January 11th, 2018.

Jan and Bob Williams got Billy from Trindledown (a local rehoming centre) in November 2016. He is now 11 and has lost most of his teeth. Billy came to the rehoming centre after his owner sadly died. After a couple of unsuccessful rehomes, he pointed his big brown eyes in Jan and Bob's direction - how could they refuse? He is a wonderful companion and enjoys a trip to Newbury riding on Bob's mobility scooter. Bob was diagnosed with MND in July 2013 and he and Billy are firm friends - whether enjoying a trip out or a quiet sleep at home.

Jan Williams

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

Woodley couple delighted by garden makeover

It was a beautiful late autumn day in October when five volunteers from the IT department at mobile phone operator Three in Maidenhead arrived at the home of Jaswant (Jas) and Joe Kaur in Woodley.

Jas, aged 72, has been living with MND for more than four years and her husband Joe has found it increasingly difficult to manage the garden as well as care for his wife. The volunteers were motivated to offer their services by their colleague Michael Litt who was recently diagnosed with MND and has made a moving video to explain his condition to his co-workers.

Introductions were made and then the team set to work with great energy and enthusiasm. The tasks that lay ahead included weeding and clearing the borders in the back garden, cutting the grass, emptying and replenishing the hanging bask and washing down the patio furniture ready for winter storage.

Armed with a selection of garden tools, the team were soon hard at work uncovering some unexpected rubble and very stubborn tree roots along the way. A quick trip to the local garden centre for winter bedding plants refreshed the hanging baskets with a colourful array of pansies, violas and cyclamens.

Fortified by tea and biscuits, and not content with just completing the original tasks, the team went above and beyond by re-edging one of the borders with bricks and then covered both borders with black plastic membrane (at their expense) and bark mulch. This means the garden will be very low maintenance throughout the winter. They then cleared everything up, swept the patio and even took away the rubbish, leaving the garden looking spick and span and ready for winter.



Three Volunteers James Eastwood, Alex Brazil, Adrian Carter, Amanda Kirby and Simon Windmill

Jas and Joe were delighted with the end result. Jas said that she had been praying for good weather all week and her prayers were answered.

The volunteers also got a lot out of the day knowing that they'd really made a difference. Meeting Jas and Joe at the beginning really gave them the motivation and inspiration to do the best job they could in the time available.

Special thanks also go to Jo Campbell and Kathy Hymas from the MND Association for their help in organising this very successful day. As a result, more volunteers from Three have come forward and are eager to help those living with MND in our area.

Wendy Gouldthorpe

Festive Morning at the Art Café

'Twas the week before Christmas and Team MND was back at the Whitchurch Art Café to serve coffee, tea and cakes on a Saturday morning for the fourth time last year.

Home made cakes were duly lined up on the table, including two beautifully decorated cakes donated by Linda Green and Samantha Morgan, coffee was brewing in the kitchen, Lin was ready with tickets for the table full of raffle prizes and soon after 10 am there was a steady stream of visitors coming in to enjoy a chat with friends over coffee and cake.

It is a popular venue for both locals walking over the bridge from Pangbourne as well as those who come to support the branch and help raise funds for the MND Association.

Art works from the local community were also for sale so visitors were able to do some last minute Christmas present shopping.

The morning flashed by, everyone was very friendly which created a lively busy atmosphere and by 12.30 pm as the last visitors left we were pleased to find we had made a total of £337.40 for branch funds.

Now we really were in the festive mood!

Paddy Lunn

Bumper cheque tribute to inspirational colleague

Colleagues of Berkshire sales manager Steve Dimond have donated a whopping £5673 to help people affected by MND.

Branch Association Visitor Wendy Gouldthorpe was presented with a giant cheque when she attended software company DMT Development Systems (UK)'s Christmas party.

Steve, who wasn't well enough to attend, sent a lovely letter thanking colleagues for all their support. This was read out by Mr Glen Demetrioff, the Canadian founder and owner of the company.

Wendy said afterwards: "I was able to share with the guests how we spend money for people living with MND in our area and I think they appreciated knowing that their efforts will be put to such good use."

DMT executive assistant Kelly Boyson said that staff had raised funds with cake sales and a 'guess the number of sweets in a jar' game. Their total was generously matched by Mr Demetrioff to produce the cheque for £3788.

In addition, donations of £1885 have been raised online at: https://www.justgiving.com/fundraising/dmt-mnd

Jane Gilbert



Association Visitor Wendy Gouldthorpe (far right) receives the cheque from (L to R) DMT's Sharon and Glen Demetrioff and Claire and Rob McBratney (VP of the European Markets)

MP Alok Sharma gives us the thumbs-up



The weather was rather unseasonal for a Christmas fayre, with a bright, warm, sunny day. However, we dug out our festive hats and had a thoroughly enjoyable day. Joanna Knott and Mary Dodds were selling MND Christmas cards while Lin Jenkins had a second stall, and sold a range of donated Christmas and Craft items.

Our hard-working volunteers (pictured left) made quite an impression on Reading West MP Alok Sharma when he visited the charity event in Pangbourne Village Hall.

Mr Sharma, recently promoted to employment minister, wasn't allowed to leave empty handed and bought some of the Association's Christmas cards to help raise awareness of MND.

Festive lunch goes down well

The traditional festive lunch for some of those affected by MND went down well and produced a heartfelt tribute to our wonderful team.

About sixty guests sat down to a glass of fizz, turkey and all the trimmings at the Holiday Inn Reading West, Padworth. It prompted one of the guests to write thanking the "amazing" volunteers for the vital work they do in supporting families.

Mrs Kirsten Wood, from Burghfield, said:" It was amazing to get know the people who took such care of my beloved father Ronnie Slater. You all spoke of him with such fondness and it's so comforting to hear how he touched other people's lives.

"But most of all, you have touched our lives and our family will always be grateful for everything you did for my dad. What a difference it made to him and to us. MND Association Reading & West Berks is filled with such kind, caring, absolutely amazing human beings! Thank you from the bottom of my heart."

Mrs Wood was joined at the lunch by other people whose lives have been affected by motor neurone disease. They all enjoyed the fellowship and pitting their wits in the popular quiz compiled once again by Alec Jenkins, who is living with MND.

West Berks Council chairman Quentin Webb also supported the annual event which included a raffle featuring three beautiful iced cakes made by Sharon Hawkins. A total of £411 was raised in raffle ticket and Christmas card sales.

Jane Gilbert



Mrs Kirsten Wood pulls a cracker with AVs Bridget Foden and Joanna Knott



(L to R) Mrs Betty Want, Mrs Pat Potts and publicity officer Jane Gilbert with West Berks Council Chairman Quentin Webb.

Father and son's coffee morning tribute



Callum Jay presents his cheque to Committee Member Mary Dodds and Association Visitor Joanna Knott

Twenty-year-old Callum Jay and his dad Paul held a successful coffee morning to raise funds in memory of a beloved mother and wife who lost her battle with MND.

They got together with friends to mark what would have been Mrs Helen Jay's 60th birthday and have now presented the branch with a cheque for £435.

The successful coffee morning was held at the Art Cafe, Whitchurch-on-Thames, and was attended by friends who used to work with Mrs Jay at Theale Green School where she was a sixth form administrator.

Family friend Claire Maslen and members of Callum's former football club, Theale Tigers, were a great help with the event, said Mr Jay, who lives in Southcote, Reading.

Jane Gilbert

Community Choir raise their voices for MND



It was another great end of term performance for Newbury Sing For Fun Community Choir. With a very generous and encouraging audience, they raised over £100 for Reading and West Berkshire MND Association when they sang at Majendie Hall in Speen on Tuesday December 5th. After a foot tapping opening with 'Blame it on the Boogie', they calmed things down a bit with 'Mad World' and 'Do you hear what I hear'. They then took the audience on a trip back to the 70's with 'Happy New Year' and ended with an uplifting Hawaiian Christmas jingle called 'Mele kalikimaka' - adding a bit of magic by pulling flower leis out from under their tops!

They have also been entertaining the shoppers outside Waitrose in Basingstoke.

Jan Williams

Nursery helps to raise awareness of MND



Anne Haines and Norman Beech

Sunday, December 3rd 2017 was rather a grey morning but this didn't stop people turning out to support the annual charity day at Glenvale Nurseries, Bradfield Southend. The lovely owners Helen and Duncan Varley hold a charity event every year and 10% of their takings on the day get divided between their nominated charities. Once again the MND Association, along with MS and Diabetes UK, was one of their chosen charities.

As usual there was an abundance of Christmas trees, holly wreaths, poinsettias and cyclamen for sale along with the usual garden centre plants. In addition to this there were a number of stalls selling cakes, chocolate, salt, glass items and much more. Helen told me that they do not charge the stall holders but each one makes a donation which all gets split between the charities.

Tucked away in the corner were the lovely Anne Haines and Norman Beech (Helen's dad) who were serving up delicious hot mulled wine and mince pies. Anne used to be a district nurse in the local area and had attended many people living with MND over the years. It was wonderful chatting to them over a glass of mulled wine.

This event raised in total more than £600. Our slice was £175 and a smaller amount will be donated to Oxfordshire branch as Helen has a friend whose dad is supported by that branch.

Our thanks to Helen and Duncan for putting so much work into the event and raising so much money and awareness for us. Thanks also to the band of helpers who made sure everyone entered and exited the site safely and to all the stall holders who were so eager to tell you about their products.

Mary Davidson

CAKES AND CARDS . . . again

For the last six years November has become the month for cooking cakes and checking I have plenty of Rod's cards printed and ready for another 'cakes and cards sale' to help towards fund raising for our branch. Home-made marmalade had been well received last year so another batch was lined up alongside the cakes.

Local shops and friends had again kindly donated raffle prizes and granddaughter Ella, having helped on the Branch Tombola stall at the Royal Berkshire Show back in September, decided to approach the landlord of a local restaurant, where she works as a weekend waitress, for a raffle prize. To her surprise he donated a £50 voucher for a meal. What a generous addition to our raffle!

Committee members Mary Dodds and Val Pearson arrived to add support to the afternoon (and test the cakes!), with familiar and new faces who appeared to buy cards, cakes, marmalade and a, hopefully lucky, raffle ticket, all helping to raise both funds and awareness for MND as well as enjoying time to chat with friends.

As school finished the grandchildren arrived so Jack was again on hand to count the money after the raffle had been drawn and proudly announce that, thanks to all who supported our sale, we had raised £445.00 for the MND Association's Reading and West Berkshire branch.

THANK YOU EVERYONE . . . again.

Paddy Lunn



Pictured right are Paddy's grand-daughter Ella Wright and daughter Sara.

You are warmly invited to a Drop-in Meeting

Tuesday 23 January 2018
12.30 – 2.30 pm

at St Luke's Church Hall, Englefield Road, Theale, Reading RG7 5AS

This will be an opportunity for you to share experiences and thoughts; to help one another and meet with friends who understand. We would be very pleased to see you. Please feel free to bring a relative or friend - all are welcome.

A selection of sandwiches will be available. Wheelchair access, toilets and car parking on site.

If you can't make this date the next one will be on Tuesday 20 March.

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

Could you be the next Branch Secretary??

If you have **administrative, organisational and IT skills** you could be the person for the branch. Our current Secretary is standing down at the AGM later this year, after 14 years, and is happy to talk to you about the role.

The Branch Secretary provides secretarial support to our committee and to help us manage effective communications within the Branch.

What does this role involve?

- To prepare, with the chair, agendas for committee and other meetings
- Take notes of branch member's ideas as they arise and make sure they are brought forward onto the next agenda
- To book venues and speakers for meetings
- To respond and deal with all branch correspondence
- To circulate appropriate information to committee members, regional staff and David Niven House (our national office)
- To ensure the effective and accurate communication and updating of group information including branch membership list
- To keep and file appropriate documentation
- To take part in branch or Association training and attend meetings as required

You will be a crucial member within the branch team and will be helping ensure that we are keeping accurate documentation.

We are looking for someone to commit to approximately 2-3 hours a week including willingness to attend monthly meetings.

Full training and induction will be provided and travel expenses will be reimbursed.

Please contact Margaret Moss on 0118 947 0871 or by email to margtony@sky.com.

Save the Date

Stoke Row Steam and Vintage Rally 2018 is proudly supporting MND Association Reading and West Berkshire Branch.

Date: June 9th and 10th, 10 am - 5 pm.

Hill bottom, Whitchurch Hill, Near Reading. RG8 7PU

More information in the next newsletter.



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