Issue 79
July 2015

motor neurone disease association

Reading and West Berkshire

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News Letter

£185K legacy is just astonishing!

There was an extra special reason to celebrate at this year's Thank You Lunch - a surprise £185,000 legacy from a West Berkshire woman whose gift remains a mystery.

Chair Margaret Moss said the branch was astonished to hear that the late Mrs Sheila Hamblin, from Cold Ash, near Newbury, had been so generous in her will.

She shared the good news to guests at the bi-ennial celebration saying: "The Sheila Hamblin Legacy of £185,000 will, we hope, fund several new initiatives to improve the care and treatment of people living with motor neurone disease (MND).

"Our good news this year is up there with the phenomenal Ice Bucket Challenge and I am delighted to be able to share it.

"It will mean that this remarkable unknown person will live on in our work. We won't forget her even though we never knew her!"

The charity has discovered Mrs Hamblin, who died unexpectedly at her home on The Ridge in April 2014, was the widow of Bryce Charles Hamblin, who died in September 2004 and is buried with her in a double grave at St Mark's Church, Cold Ash. She left the money specifically to the branch of the MND Association covering the Newbury area even though she has no known connection.

It was part of a £2.3 million estate shared between 12 local and national good causes. Seven people also received gifts of £30,000 each.

The High Sheriff of Berkshire Mr David Bertie and his wife Catherine were among the 100 guests of the branch at the Basildon Village Hall event in April who were delighted to hear how its share will be spent.



**Dr Martin Turner and
High Sheriff David Bertie**

The plans include spending:

- £60,000 on the key appointment of a respiratory physio nurse,
- £80,000 on two research projects,
- £10,000 on training care agency workers,
- £4,000 for counselling services and
- £6,000 on training courses for health professionals and carers.

Guest Dr Martin Turner, consultant neurologist and clinician scientist at the Oxford MND Care and Research Centre, said the money would make all the difference to stem cell work being carried out by colleagues there.

The High Sheriff also spoke movingly about his father-in-law who had lost his battle with MND. Mr Bertie pledged to do all he could to support the work of the Association during his period of office and has since invited a representative from the branch to a reception at his Binfield home in the Autumn.

Specialist nurse Carol Allen was honoured at the lunch with the Association's Extra Mile award after her ten years caring for people with rare neurological conditions.

Mrs Allen, who retired in July, was presented with the badge and certificate for working tirelessly, often out of hours, to help relieve the concerns and fears of many people living with MND.

Margaret Moss said: "Carol has been the prop, the ear, the wise advisor to us all and the vital link to make sure that people living with MND are in control of their own treatment at home and kept out of hospital where possible."

*See page 2 for separate story for the branch's farewell to Carol and welcome to her successor Jane Owen.

Jane Gilbert

Registered Charity No 294354

Happy Retirement Carol!



Carol Allen cuts her cake

Specialist nurse Carol Allen was treated to a cake and flowers when she attended the last branch drop-in session before her retirement on July 3rd.

Volunteers and people living with MND and their carers paid tribute to all her wonderful care and support since taking up the pioneering post ten years ago.

Carol said: "I have always felt very privileged to work with people at such a difficult stage in their lives, to support them and help them live with MND and other rare neurological conditions.

"The neurology and neuro rehab team at the Royal Berkshire Hospital has been incredibly supportive. We have such a good service set up here."

Carol, who lives in Thatcham, now plans to spend more time with her husband Cliff who retires soon and her young grand-daughter.

The specialist nurse post was set up after West Berks Neurological Alliance and the MND Association's Reading and West Berkshire branch funded it for two years at the cost of £90,000.

An impact study conducted by Reading University showed the vital role had saved the NHS money by stopping people going into hospital by being able to manage their care at home. The post was then funded by health chiefs and will continue with Carol's successor Mrs Jane Owen who has taken over the reins.



Jane Owen

Jane, from Whitchurch, near Pangbourne, previously worked at the National Prion Clinic in London supporting people in the UK with a group of rare conditions that affect the nervous system.

The 40-year-old mother of a toddler son has a neuro science degree and a background working with neurological conditions including a spell as a ward nurse and in teaching.

Jane also attended the branch drop-in during her second week in the job and said: "It will be a challenge and I am certainly looking forward to getting stuck into it."

Amongst many others attending this drop-in was Mrs Pat Potts of Tilehurst. She donated a cheque for £4000 to the branch in memory of her late husband Bill who died of MND. Mrs Potts was left this money in her aunt's will and generously decided to donate the money to help people living with MND.

Jane Gilbert



Pat Potts, Jane Gilbert, Carol Allen, Margaret Moss, Joanna Knott Alec Jenkins and Anne Smith

Top up from school's wine bluffs

A fun-filled Call My Wine Bluff evening at Pangbourne College has given a top-up to branch funds.

Harbinger Housemaster Charlie Sutton and his wife Laura chose the Motor Neurone Disease Association to benefit in memory of the father of two of their pupils. Mr Tony Wooding, a research chemist from Streatley, died in April last year, aged 52.

Mr and Mrs Sutton handed over a cheque for £1,251 to chair Margaret Moss at the Thank You Lunch for supporters in April at Basildon Village Hall.

They were joined by Mr Wooding's wife Amanda who praised the school and the charity for the support she and her family had received since her husband's diagnosis with the devastating condition less than two years before he died.

Mr Sutton said the MND Association had now been chosen as the house charity and promised more money to come.

Jane Gilbert

Neuro Nine in peak form

Nine Newbury friends and work colleagues were in peak form for a tough weekend of climbing to raise funds for the MND Association.

They successfully took on the Three Peaks Challenge – conquering Ben Nevis, Snowdon and Scafell Pike – and have collected a massive £8,000 for their efforts.

Group member Lisa Goldsworth was kept going by thoughts of her grand-father John Austin who died of MND in 2011.

She said: "I had a picture of Grandad with me as I climbed and it certainly inspired me! I'm sure he would be proud, or think I've lost the plot!"



Lisa , fourth from left, with the rest of the team and their guide

Lisa and five others in the group work for the community-based neuro rehab team in Newbury. They were joined by her husband Guy, Lisa's best friend and a former colleague.

They completed the gruelling challenge just short of their target in 26.5 hours.

Lisa explained: "They allow 25.5 hours due to the minibus only going certain speeds so we were 1hr off target. Snowdon was gruelling and we were all so tired we were just so pleased that nine got to the summit!

"We didn't have brilliant weather for Ben Nevis at all, but Scafell and Snowdon we had great views for both summits!

"We feel very proud of what we have achieved. Never again though, definitely don't want to see a mountain for a while!"

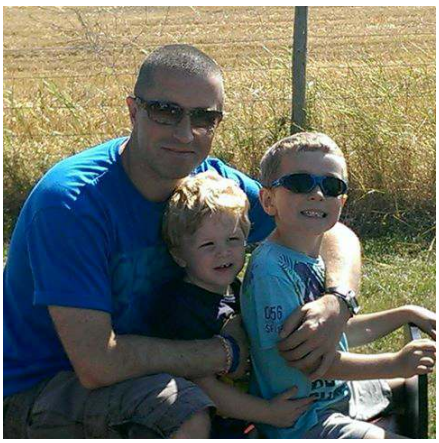
The delighted team smashed their £5,000 target in aid of the Association and hope to donate a significant amount over that figure to the branch so that it can be spent locally.

To donate to the group visit:

www.justgiving.com/NewburyNeuro-9

Jane Gilbert

TrekFest tamed!



Steve with sons Sam and Alex

Dad Steve Woodrow completed a 13-mile trek across the Brecon Beacons raising £1,000 in memory of brave, funny and close family friend Derek Prior.

Afterward Steve, aged 42, who lives in Thatcham with his wife Claire and two sons Sam, aged 7 and three-year-old Alex, said: "TrekFest 2015 tamed!

"Huge thanks to all those that sponsored me. Taking on TrekFest is no mean feat, it was tough...there's no getting away from that. Also, my company MACMILLAN Distribution of Basingstoke have matched what I raised."

Derek, who was a founder member of the Reading and West Berkshire Branch in 1987 with his wife Mary, sadly lost his fight with MND in 1990.

Mary, now a key member of the branch with her second husband Barry Dodds, said:

"I know that Derek would have been so very proud of Steve for giving up his precious family time to support people and their families living with MND and for supporting our branch Reading and West Berkshire. What a star he is!"

Jane Gilbert

Footie fans' words come back to bite him



"If Reading get to Wembley, I'll walk there," declared Robert Leigh in some friendly banter with members of Henley Golf Club.

Little did he realise that two months later the 25-year-old club steward would be eating his words.

Big-hearted Robert carried out his threat and walked the 30 miles from Wembley to Henley raising more than £6,000 in sponsorship from his amazing effort.

Rob explained: "I am a big Everton Fan and after they got knocked out of the FA Cup in their first match (the third round) I took the usual abuse & banter that goes with being a fan of a 'less-popular' team.

"During the to-ing & fro-ing one of our more colourful members Reece Pigden joked: 'Reading FC are on their way to Wem-ber-ley!'.

"Needless to say I didn't agree! I brushed off the comment saying:

"Reece, if Reading get to Wembley, I'll walk there!"

Two months later having beaten Bradford the Royals were on their way to Wembley and Robert decided there was only one charity to walk for - he chose the MND Association as a tribute to golf club stalwart Peter Phillips who was living with MND. Peter sadly died the month after Robert's walk in April but was delighted to hear how much money had been raised for the Association.

Robert said: " Peter was at the core of our golf club, not to mention one of Reece's oldest and best friends which is why, when I realised I'd be walking, there was only one charity to walk for."

He did the walk on the day of the semi-final and was advised to walk back to Henley rather than finish at Wembley Stadium on the day of the match. He eventually reached Henley Bridge where he was met by well-wishers in The Angel pub who joined him for the last couple of miles to the clubhouse.

Robert is pictured presenting donated cash to our treasurer Ed Gryglaszewski.

To make a donation visit:

www.justgiving.com/robswembleywalk

Jane Gilbert

Thank you Andrew Wall

On behalf of Branch Chair Margret Moss, I met with Andrew Wall to thank him for his good work and efforts in setting up our branch Facebook page in November 2014. He was unable to attend our branch thank you lunch in April, and has continued to provide additional support to Mary Dodds for the administration of our Facebook page. Andrew Wall has a computer repair business and is Unit Chair for Reading Sea Cadets. He prefers to stay in the background and to help us out when required. However on this occasion, it was pleasing to meet up with him and to extend our gratitude for his expert assistance and continued support to Reading & West Berkshire MND Association.

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Barry Dodds



MND Parliamentary lobby



Polly O'Gorman (left) and Branch Chair Margaret Moss (right) with Good Morning Britain TV presenter Charlotte Hawkins

Over 130 volunteers and 75 parliamentarians attended – a record turnout for a MND Association parliamentary event! Though having been invited, none of our local MPs were able to attend but Alok Sharma, MP for Reading West, sent his Senior Researcher so we were able to tell him about the services and situation in this area.

The networking that was enabled at this event, meant that local branches could meet and compare notes, exchange news about people who had moved from our branch to another and to hear stories from some others living with MND.

Many from National Office were there too, as were the wonderful Campaigners (including our own, Helen Findlay).

After 33,360 signatures of support for our MND Charter were presented to No10 Downing St, MPs were invited to a reception with light refreshments.

We were near the Palace of Westminster but not in it!

Since we had been asked to wear our blue T shirts, the room was a sea of blue, MPs could only be impressed by the number of people, volunteers and those with MND, who had travelled far for the chance to reinforce the need for good, timely, local and national services.

One of the Association's Patrons provided a popular photo opportunity - Charlotte Hawkins whose dad had had MND. She was a very touching speaker after Sally Light, our CEO, had given a hard factual speech. But the most touching for me, was an unscheduled speech from Eric Rivers (of DIY SOS fame). Eric uses an eyegaze and made a powerful speech not having a voice; 'if the eyes are the window of the soul, the voice is the breath of the soul'.

Margaret Moss

Golfers' tribute to three friends

A golf day in memory of three friends has teed up £1,300 for the MND Association.

Tony Page and Tony Wooding, who both died last year of motor neurone disease, were keen players at Goring and Streatley Golf Club. Mr Wooding often played a round before work with Laurence Gardiner who recently died of a brain tumour.

Organiser club steward, Keith Sessions, said the popular members had inspired the day and a great time was had by all 60 golfers who took part.

Mr Wooding's widow Amanda presented a trophy for the highest individual score and there were prizes for nearest the pin and the longest drive before a Champagne meal with a raffle and auction.

Mr Sessions added: I have seen how MND affects people. We will definitely do it again."

Jane Gilbert



It's raining Rock'n'Ale!

Wet weather failed to dampen the spirits at this Summer's Caversham Rock'n'Ale Festival.

Local bands were enjoyed over pints of beer and a hog roast as music fans rocked the night away inside a dry marquee to raise funds for the MND Association.

First run in 2013, the event was inspired by Mrs Angela Fung – a close family friend of the festival's organisers – who died from Motor Neurone Disease in December 2012.

Many friends of the popular teacher were determined to enjoy the annual event on the playing fields at St Anne's School in Washington Road. They were joined by her husband Daniel and two of their four sons.

Branch chair Margaret Moss, also went along with Association Visitor Jan Gryglaszewska and treasurer Ed Gryglaszewski to help raise awareness of MND.

Angela's friends from the parish of Our Lady and St Anne's run the community event to raise funds for people living with MND and the Association is a major beneficiary. All those involved gave their time and energy free of charge as did the bands who performed on the evening.

Afterwards they said: "A big, big thank you to everyone who helped make this such a successful event and an especially big thank you to all those who braved the rain to come along and enjoy the evening. The sun shone in the end.

See you all next year!"

Watch a video clip of the event highlights:

www.youtube.com/watch?v=ukduhs7zXYQ

Jane Gilbert



Steve Casemore, Paul Webber and Les Allen brave the weather

'Thank You for a Wonderful Effort!'

On Thursday 11 June Martin Turner, Kevin Talbot, Rachael Marsden and Nicola Gabriel, all members of the Oxford MND Care Centre clinical team, began a four day cycle ride to raise awareness and funds for the MND Association.

The team set off from David Niven House in Northampton, cycling 150 miles to finish at the West Wing John Radcliffe Hospital in Oxford. They stopped off at all the regional hospitals on the way - Milton Keynes, Stoke Mandeville, High Wycombe, Royal Berks, Great Western Hospital, Swindon then back to Oxfordl.

They aimed to raise £2,000 for the association and to date have broken that target @ £2,563 and counting. If you would like to contribute, please go to the just giving website:

www.justgiving.com/oxfordmnd

On the first leg of the ride, the team were joined by our CEO, Sally Light and TV Anglia were on hand to record the start of the journey. Alex Thompson, a young research student, joined them on day two.

They arrived at Reading, tired but exhilarated that they had made it and were looking forward to the last leg of their journey the very next day.

In spite of their tiredness, the group joined members of the local branch for drinks and canapés on a lovely summer evening in Joanna Knott's beautiful back garden in Pangbourne.

We would like to thank all the riders for their commitment, stamina and passion for what they do. You are amazing!

Val Pearson



Prof Kevin Talbot, Alex Thompson, Dr Martin Turner, Rachel Marsden and Nicola Gabriel

Newbury Rotary Charity Walk

On a fine dry day in early May when the countryside was looking very spring like with growth, seven of us joined the Newbury Rotary Charity Walk. Paul Jenkins, who is used to longer walks, had set off earlier as he was taking the longer route so missed the photo shoot!

Starting at the Victory Room we were given maps and a description of the route. We soon walked out of Bucklebury across fields and onto a road. Walking at a gentle pace, we were overtaken by a group of cubs and other youngsters.

There was plenty of variety along the way - woods full of bluebells, uneven paths underfoot, tarred roads and rutted tracks.

As we approached a bend in the road, there waiting for us was a wheelbarrow! Outside a house and gate but empty and unattended! A photo opportunity waiting! And the temptation was too great, Anna was persuaded to sit in it (I knew it would be too difficult a manoeuvre for me - I might not get out afterwards!) Here's the result!!





Team MND at the start of their trek

Lots of conversation on a five mile walk, catching up on things, enjoying the scenery, discovering a new part of Berkshire, it's a good companiable day - I'd recommend it to you all! Join us next year maybe? I'll remind you!!

But Newbury Rotary Club are to be applauded; the organisation is impeccable; the map and directions were supplemented en route with little yellow markers or stickers to show the direction we should take. Well done once again guys!

My favourite point, after the wheelbarrow, was to find a ford over the River Pang (we didn't have to walk through the water though as the council had built a footbridge for us!) - Not a common site nowadays!

Margaret Moss

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

EQUIPMENT AVAILABLE TO BORROW

In our store, we currently hold the following items of equipment which are available to borrow by any person living with MND in the Reading & West Berkshire area. The items have all been donated and they include:

- **A battery powered Scooter**
- **A folding lightweight wheelchair**
- **A mobile toilet** (useful if staying somewhere where the loo is not easily accessible)
- **A trolley/walker**

Other items become available from time to time and so it always worth asking your Visitor or Joanna Knott (0118 984 4495) if there is something you feel you need that we may have been given.

Dr Jane Bywater at the AGM

At the AGM in May, our speaker was the Palliative Care Consultant from Duchess of Kent Hospice, Dr Jane Bywater.

In answering the question 'What is Palliative Care?, Dr Bywater explained that it can be different for different people as she discovers when she asks the following questions as posed by the Reith lecturer, Atul Gwande:

- How can I help you have the best possible day?
- What is your understanding of where you are with your condition or your illness at this time?
- What are your goals if time is short?
- What are your fears and worries for the future?
- What outcomes would be unacceptable to you?

Having discussed these questions, the doctor needs the patient and his or her family to consider what they want for the end of their lives, so the question is then asked, "on a scale of 1-5 where do you fall on the continuum between letting me die without any medical intervention at all, to 'don't give up on me no matter what, try any proven and unproven intervention possible'." In other words, Palliative Care is that care which takes fully into account the patient's feelings and wishes about their condition and how they want to spend the rest of their life.



Margaret Moss with Dr Jane Bywater

Dr Bywater also considered the question of what 'Wellness' is. We normally consider wellness to be a physical thing, but actually there is so much more to it than that – what about emotional, spiritual, intellectual, environmental, social and occupational wellness?

Often with a life limiting illness, there is not an awful lot that can be done to improve physical wellbeing apart from alleviating symptoms, but there is much to be helped in the other aspects of 'wellness'.

One of the most important of these is the effect on mental health of the natural environment and the sense of well-being that can come with our engagement with the natural world.

Dr Bywater then quoted a couple of evidenced based pieces of research that indicated the strong relationship between green space and mental, emotional and spiritual health. Palliative Care considers the **whole** person and aspires to make life as good as it can be for any one individual, and in so doing, I would suggest, can make living with a condition like Motor Neurone Disease so much easier to accept.

Joanna Knott

Great Support makes all the branch does so much easier!



When we were first bold enough to take a stand to the Royal Berkshire Show some years ago, it was something we had no experience of. Everyone got stuck in and we did it - but really we over did it! A sensible voice commented that 'if we had our own tent, we'd not need to hire one and I'll look after it and put it up and down and store it'.

That was the beginning of a long involvement and practical support; countless events and incidents where Barry Dodds (Mary's husband) worked, supported and entertained us! His continued support at the Royal Berkshire Show at Newbury and numerous other events warrants a public thank you.

Need some help? Barry's there. Have a problem to solve? Barry knows just the person!

Thank you Barry for all you do - you are a wonderful supporter of the Branch and of Mary. As one of our committee would say "You are a Star!"

Margaret Moss

Berkshire Carers' Service

At a recent MND Carers' Support Meeting, Shirley Pays, the Outreach Worker for West Berkshire, came to talk to us and described her organisation as 'a one-stop shop for unpaid carers, whether they be friends, neighbours or relatives'.

Signposting is a big part of their role and they have a free Helpline Number, **0800 988 5462,** for the whole of Berkshire which is manned from 9am to 5pm Monday to Friday.

It is a good idea to register with them as then the Carer will receive a Newsletter every quarter with information and advice.

Berkshire Carers run Pampering and Education events as well as Support Groups which can be very helpful.

They do urge every Carer to register with his or her local GP Surgery as a Carer, because although the GP will know this, the information may not necessarily be on the Surgery Carers' Register, and it is important that they have an accurate figure of the numbers concerned on their Register.

Joanna Knott





Pictures show Scruffy and Keith Hood with Scruffy

Do you remember Scruffy?

Hello I am Scruffy, perhaps you remember me?

I used to live in Berkshire and I did some very exciting things with Dad (Keith Hood) for fundraising.

I have recently sent £200 to the branch treasurer, raised mostly with Mum (Fay Hood) at her girls' nights out. She has planned a fourth Wedding Anniversary Party for me & my wife as well as a garden party in the summer - both of these will be for fundraising too. These funds are in memory of our good friends Graham and Maureen Hodgetts of Thatcham. We still miss them very much.

We do like getting the Newsletter even though we are in Norfolk now.

Thank you Scruffy!

Margaret Moss

Marbles - and more

Can you help us, please? We are looking for marbles to fill a large sweet jar for our MND stand at the Royal Berkshire Show in September.

We are also looking for small items for our stall.

If you can help in any way please contact Mary Dodds on 0118 941 4956 or by e-mail at MaryDodds@mndrwb.org



Wheelchair Project

(article reproduced in part from 'The News')

We have appointed the Institute of Health and Wellbeing at the University of Northampton to conduct an evaluation of the Wheelchair Project.

As part of this evaluation, we are seeking feedback from wheelchair users or carers on their experiences of mobility assessment and wheelchair provision from their local wheelchair service.

This will take the form of a questionnaire which should take l0~l5 minutes to complete.

We would like as many wheelchair users as possible to participate in the survey as it will be of great value not only to our evaluation, but also to gain more information on wheelchair provision in general.

The following is a link to the questionnaire:
https://northampton.onlinesurveys.ac.uk/wheelchairprovisiononlinesurvey

For queries about wheelchair provision, please email: wheelchairqueries@mndassociation.org

For more information about the Wheelchair Project visit: www.mndassociation.org/wheelchair-service .

Fantastic Fundraising

We have had the most marvellous "season" so far this year. We attend as many fetes etc as we can, and any Saturday or Sunday that we have "free" we car boot sale - Saturday at Prospect Park and Sunday at Thatcham. At the time of writing we have just passed our £4,000. We have set a season target of £5,500.

Our main stall at all the fetes, so far this year, has been the Lucky Bag Game. This involves 100 numbered bags, customers pay £1 per ticket with a prize every time. As we have been so successful we are running out of prizes, so we are branching out to a Sweet Tombola at some of the remaining events. At each event we also have a Lucky Dip, and also



sell a few nice items.

The picture above shows Lin at Bucklebury Boot Bazaar before a sudden gust of wind blew the marquee down!

All the car boot items are donated, usually second hand items. We generally have a supply of jams, chutneys, plants etc - whatever I get time to make. I would be happy to receive offers of cooking apples when they are ready, as I have lost my usual source, since the loss of my dear dad.

Anything that any of you have that is no longer needed we can use/sell. We often get odd toiletries from one person, a nice basket or container from another, some nice tissue paper from a third - we marry them up, wrap them in cellophane, add a nice bow - hey presto a lovely gift!

We also need clothing/shoes. Another "must have" are nice paper or cardboard carrier bags. We use these for the Lucky Bag Game. Empty jewellery boxes are another thing - anything you have that might be suitable please call 0118 9412738 or email rlp.Jenkins@Tiscali.co.uk

Jenko & The Bear are walking the Cotswold Way this year. As this path is over 100 miles long they are splitting the walk over two separate weeks. They did the first half of the walk, starting at Chipping Campden during May. They will be completing Painswick to Bath during the first week of August. Any sponsorship would be greatly appreciated.

A full report of their walk will appear in the next newsletter.

Jenks prepared for this by "walking" the Reading Half Marathon and joining the team for the Bucklebury Walk (coming first, despite getting lost twice). He has also joined the MND Association 'Beat The Street' team - but appears to be one of the few who actually clocked up any miles - perhaps next year many more of us can take a more pro active approach to this wonderful scheme!

'Beat the Street' Reading is designed to encourage and inspire communities in Reading and some of the surrounding villages to walk to school, work and the shops instead of taking the car.

More details of 'Beat the Street' at: (http://reading.beatthestreet.me/

I am just getting the Salvage Team prepared for the Reading Music Festival. From midday on Monday, until about 4.00pm on Tuesday, we are "registered" to go in and salvage as much as we can. This year I hope to get a small army of us, and really collect a lot.

Last year I collected over 70 folding chairs, 11 tents, 17 pairs of wellies, and more duvets, sleeping bags etc than I can remember. All this had to be stored at our house. This year, with adequate storage in place, and lots more help, we should really be able to collect a lot.

Finally, I would like to say how very much we enjoy our work - not only are we raising lots and lots of money, but also lots of awareness, People are actually looking out for us now! We are "reaching out" to many people, which makes the cold, the tiredness, aching bodies all well worth it!

Thanks to my sister Ruth, her husband Andy, and all our family and friends for all their help this year.

Lin & Paul Jenkins



Paul and Ross at the start of their walk in Chipping Campden

Good news

The MND Association Reading and West Berkshire branch is one of three charities chosen by John Lewis Reading's Community Matters scheme for May, June and July. Be sure to put your green token in our box outside The Place to Eat so that we get a good slice of the £3K share-out.

The Good, The Bad & The Ugly

Like the classic spaghetti western there are 3 parties in this tale of buying disability aids.

Firstly The Bad is a company based in Lancashire (it can't be named for legal reasons): On 12th April 2014 I ordered a trolley/walker, an electric riser seat and a wheelchair cosy from them. Two weeks later I had to chase up the order.

The goods arrived early May. There followed a whole litany of problems:

(i) part of the mains lead was missing from the riser seat. When they sent the other part it only had a 2-pin plug. I had to buy another lead with a 3-pin plug.

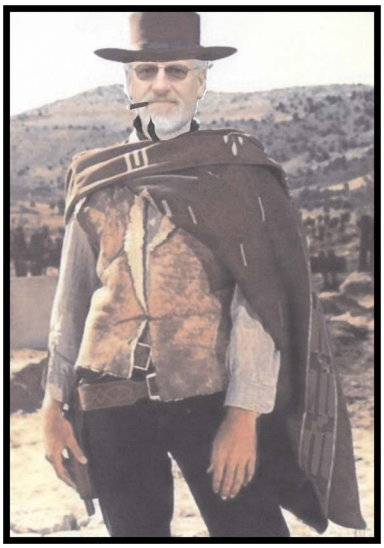
(ii) about 3 months after I started using the trolley/walker a brake cable broke. They asked me to email photographic evidence. I then had to chase them up twice, the second time threatening them with Trading Standards. Finally 2 weeks after emailing the photographs they replied offering either to take the item back for repair or to refund £5 if I arranged the repair myself. As I wasn't greatly impressed with the service I had seen I opted to repair it myself. It then took months to get the £5 refund.

(iii) as the winter days got colder I started to use the wheelchair cosy. Within a very short time the zip started to come undone in the middle. Finally in early January, after about 2 month's actual use - obviously I didn't use a fleece lined cosy during the summer - it had reached the stage where it was unusable. At the same time the second brake cable on the trolley/walker broke. I emailed them but they refused to do anything about either item. My OT emailed them citing The Sale Of Goods Act. They sent their reply to **my** email address in error - that sums up their efficiency - it contained inaccuracies, half-truths and assertions. **I would suggest you avoid them**.

Secondly The Good is **The Ability Superstore**: I contacted a very nice lady there named Sandra and when I said that I needed to replace a faulty wheelchair cosy and explained about the bad experience from the other supplier she showed me a much better quality one and offered me a discount. It was at this point I donned my cheeky hat and asked her if she would be prepared to offer a discount to any plw MND and she offered a 10% discount. If you email Sandra at: heretohelp@abilitysuperstore.com she will give you a link to get the discount. Please do not abuse this offer.

Thirdly The Ugly: I've just realised that, as the third party in this tale, that's **me**.....and I did so see myself as the Clint Eastwood character!!!

Alec Jenkins



'THE NEWS'
from the MND Association ONLINE

This publication is very useful and informative.
You can view the latest edition and archived electronic copies at
www.mndassociation.org/get-involved/volunteering/volunteer-zone/news-2

Wanted

Tombola prizes and good quality books, particularly children's books, for the Royal County of Berkshire Show.

Please contact Mary Dodds on 0118 941 956 or by email MaryDodds@mndrwb.org

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



Summer Afternoon Tea Party

WEDNESDAY 5 AUGUST 2015, 2.30 - 4.30 pm

at Reading Canoe Club The Warren, Caversham, Reading RG4 7TH

We would be very pleased to see you. Everyone is welcome to our Summer Tea Party at the Canoe Club, overlooking the River Thames. Parking is limited and anybody who has a wheelchair or needs access will take priority. There will be somebody on duty to help with parking.

If you have not been to the club before and need help in finding it, or if you have any special needs, please contact Val on 0118 9789063.

Barge Trip

Once again Newbury Rotary Club members crew the Rebecca for a week and have offered the branch a day on the water on 10 September.

We will be contacting some of you who have MND to ask if you want to join the trip with your carer. It is fully accessible with a ramp and a lift so please think about it - we are limited to one large wheelchair due to space in the cabin however.

We'll start at Newbury West Mills at 10.30 and end at Kintbury at 15.00 and can help with lifts etc is necessary.

Refreshments and lunch will be provided and committee members will be there too!

Margaret Moss

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Top up from school's wine bluffs

3 Neuro Nine in peak form
Trekfest tamed!

4 Footie fans' words come back to bite him
Thank you Andrew Wall

5 MND Parliamentary lobby
Golfers' tribute to three friends

6 It's raining Rock 'n' Ale!
Thank you for a Wonderful Effort!

7 Newbury Rotary Charity Walk
Equipment available to borrow

8 Dr Jane Bywater at the AGM
Great support makes all the branch does so much easier

9 Berkshire carers' service
Do you remember Scruffy
Marbles - and more
Wheelchair project

10 Fantastic fundraising
Good news

11 The Good, The Bad and The Ugly

12 Future Events

Please support us at
The Royal County
of
Berkshire show

19th and 20th of September

Reading & West Berkshire
mnda
motor neurone disease association

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