Thank you to all our wonderful supporters who helped to raise a staggering £7 million in donations from the Ice Bucket Challenge.

In just two weeks the MND Association was given the equivalent of almost six months income and all those shivery soakings helped massively to raise awareness of this devastating disease.

Already the funds have allowed the Association to immediately bring forward certain projects that were in the pipeline and to fast-track new ideas including new Young Person’s Grants. It is determined to spend the money wisely and is consulting with the MND community to ensure the views of people living with the disease and their families are taken into account.

Here in Berkshire people of all ages seized the crazy challenge and, although most of the donations went directly to national office, some have boosted branch funds. Mrs Jean Towner, of Wokingham, sent treasurer Ed Gryglaszewski a generous gift of £2,000 after seven members of her family, including her four-year-old great grandson, took the challenge. In memory of her husband who died of MND in 1998.

Supporter Michael Morrison, from Bucklebury, got the ball rolling in West Berkshire by getting drenched in front of the crowds at Chapel Row Fayre in August. Within minutes onlookers were eager to take the challenges too and TV’s Chris Tarrant, who was enjoying the fayre, was happy to oblige by soaking Hannah Preston, Laurie Purcell and Nicola Packman.

Michael Morrison got his own back at the Royal County of Berkshire Show in September when he doused Newbury MP Richard Benyon, whom he nominated, and branch chair Margaret Moss. The soakings, watched by the show crowds, went out live on BBC Radio Berkshire and listeners heard branch patron Richard say that he was happy to participate for the cause having lost two uncles and two friends to MND.

“What’s a bit of indignity for a good cause?” he said. Watching proudly in the crowd was the MP’s aunt, Lady Hallifax, whose late husband Admiral Sir David Hallifax was one of his uncles.

Staff at a West Berkshire pub drenched themselves in ice-cold water in memory of a regular customer who died from MND earlier this year. Ten staff members at the Butt Inn, Aldermaston, took the challenge as a tribute to Gavin Henderson. The event raised £328 and one of the team, Andy Slade, also competed in the Great North Run to raise even more funds.

There was no running away for The Newbury Neuro Nine whose cold heads and warm hearts piled on the pounds for the Association. The group, from the Neuro Rehabilitation Team within the Berkshire Healthcare Foundation Trust, will next attempt the tough Three Peaks Challenge in June 2015. One of the team, Lisa Goldworth, lost her granddad John Austin, who was supported by the branch, to MND.

Story continued and more pictures on page 2
Several of the younger members of Tilehurst Amateur Dramatic Society raised £60 from their challenge. Roger Holmes, of TADS, said: “Members felt that it was a simple donation to a good cause.”

Former branch committee member Colin Moss, who is living with MND, bravely took a dousing from his partner Shan Mills in their Wiltshire garden and nominated three friends to follow suit. He said: “I was diagnosed with ALS, which is the most common form of MND, nearly 13 years ago. As I have done the ice bucket challenge, so can you!

My challenge was in memory of the many friends I have lost during this time and in the hope that a cure will be found sooner rather than later.”

You can still donate by:
- Visiting our branch Just Giving page https://www.justgiving.com/Reading-and-West-Berks-branch-MND-Association/
- Texting ICED55 £5 (or other amount) to 70070
- Sending a cheque made out to MND Association Reading and West Berks to Treasurer, 27 Ashton Road, Wokingham RG41 1HL

Jane Gilbert
Canal cruise was simply magic

A leisurely cruise along the waterways of West Berkshire was simply magic – thanks to our kind hosts at Newbury Rotary Club.

Rotarian John Winchcombe literally conjured up a few clever tricks to entertain our guests as we sailed aboard the purpose-built boat Rebecca from Newbury to Kintbury.

The club hired the well-equipped craft from The Bruce Trust for a week in September to take groups from seven different charities. Their skipper Eddie Webb was ably assisted at the locks by Avril Cole, John Winchcombe and John Jolly to whom we are very grateful.

Our crew – Margaret Moss, Joanna Knott, Mary Dodds, Jan Gryglaszewska and Jane Gilbert – served up Bucks Fizz and tasty treats for people living with MND and their carers who joined us for the memorable day.

Jane Gilbert

More ice bucket stories

Neil Woodrow of NSK Precision Engineering donates £250 to Branch Committee member Mary Dodds and Chair Margaret Moss. This sum includes Neil’s Ice Bucket Challenge monies.

Neil’s friend Derek had MND many years ago and said “We all have our own suffering but there are some who suffer more!” It was because of Derek’s wife and friends that this branch was founded.

Margaret said “We aim to continue and build on the great work they started all those years ago.”

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
At the open meeting on October 8th, Dr Malcolm Proudfoot, PhD, from the Oxford Centre for Human Brain Activity gave some mind-boggling information during his presentation to the branch at the Holiday Inn Reading West. There is no diagnostic test for MND, but he spoke about ‘New insights into MND from Magnetoencephalography’, stressing that human beings were quite unique, with a brain very different from most animals. Did you know that MND is only found in human beings? Multiple Sclerosis, a physical condition, is found in other animals, but not MND. Why not? Why are we so special?

In our systems, twenty billion neurones work independently – yet when neurones work together, brain connections are strengthened. However, MND affects these networks and it is the impact on these networks, not individual cells, which is so damaging.

Only eight scanners in the UK are capable of such analysis and are used exclusively for research purposes. The scanners are kept in a ‘big box’, isolating them from the earth’s magnetic field. Before being assessed, each person’s head shape and size is measured before scanning, as each individual is totally unique. Eye movements are then monitored, measuring oscillation abnormalities.

The diagrams showing the brain activity used to resemble a painting by a three-year old child - all mixed up with no recognisable structure! The problem is analysing such vast quantities of data, comparing brain activity in that of a healthy person to someone with MND.

One of the hoped-for outcomes is to use this data to assess drug effectiveness, by measuring brain activity pre- and post-drug use. However, there is a vast difference between showing an effect in a Petrie dish and on a real person. The hope is that it will now be more possible to get reliable readings so that subtle changes can clearly be seen before physical symptoms appear.

It is important, not simply to record the drop in the strength of such connections, but to explain what happens. Only when it is possible to explain the processes involved, will we be able to develop successful drug treatments for a diverse, highly complicated condition.

We were all very impressed by the efforts being made to crack the problem, if a little overcome by the complicated process involved.

Val Pearson

£1,500 windfall from Henley Freemasons

A generous donation from Shiplake Lodge in Henley will help to make a difference to people in the Thames Valley who are living with motor neurone disease.

Past Master Andrew Watson-Smith and his wife Louise are pictured presenting the cheque to branch chair Margaret Moss at Chapel Row Fayre, near Reading, this Summer.

The cash was raised at a garden party for Freemasons and their wives held at the couple’s home in nearby Beenham. For Louise, who lost her 71-year-old father John Carter, from Earley, to MND in 2001, the Association was the obvious charity to benefit from the event.

She said: “We are so pleased to be able to support the MNDA which, as you know, is a charity very close to my heart. We hope our donation helps in some way to support those suffering with this terrible disease.”

Jane Gilbert

Picture, right shows Branch Chair Margaret Moss receiving the cheque from Andrew and Louise Watson-Smith
Royal County of Berkshire Show 2014

Our presence at the Royal County of Berkshire Show 2014 held at the Newbury Showground proved to be our most successful to date.

Over 60,000 people attended Berkshire’s biggest event over the two day period and our MNDA stand was well supported by the passing crowds.

MND awareness raised on the back of the “Ice Bucket Challenge” phenomenon was also in evidence as visitors dropped in to support us by trying their luck on our tombola, buying MND merchandise or putting their monies into our collecting buckets. Adults and children were keen to tell us about their completed challenges and details recorded on media sites and mobile phones.

This year we received over 400 prizes for our tombola which Mary Dodds had expertly packaged and displayed along with MNDA bags for life, teddy bears, orangutan & meerkat soft toys, and Christmas cards. Saturday was a busy day with queues forming to have a go on our tombola and by mid Sunday we were practically sold out.

Our wonderful team continued to dispatch MNDA literature and then tried some amusing selling techniques to dispose of the second hand books and remaining items. These techniques were rewarded by people being very sympathetic and donating extra monies to cover their free books or the number of books actually purchased.

Not forgetting that the success of our MND stand this year includes the generosity of all who contributed to the tombola with their unwanted gifts and the private funding for the stand pitch. As we were virtually sold out this year, if you have any items that you think might be suitable for next year’s event, please remember the Branch. Contact details are on the last page.

Finally a bigthank you to everyone involved, and to all of our wonderful supporters who make this branch event very worthwhile.

David & Lorraine Claridge with their son James visited the show and handed over £50 from their completed Ice Bucket Challenge which was gratefully received by Mary Dodds for the branch.

As you will have seen elsewhere in this newsletter, the Branch Chair, Margaret Moss, and Newbury’s MP Richard Benyon were great sports and completed their Ice Bucket Challenge at the show and this went out live on BBC Radio Berkshire during the Saturday morning program with Henry Kelly.

Our team MND and young helpers were truly amazing on both days; however special thanks to Alec & Chris Jenkins, Brian & Brenda Rayner for their support on our stand, Alisha Taylor for her efforts on the tombola, Samantha McCarthy & Chloe Hawkins who made the wrist loom bands, Neil Woodrow who helped with the stand erection & dismantling, and Netta Thorne who helped with the clear up after the show closed.

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Barry Dodds
Carer’s Conference

Thanks to a generous grant from the NHS Partnership Development Fund, Clinical Commissioning Groups, Berkshire West Federation, the Branch was able to put on a Conference specifically for carers of people living with MND. It duly took place on Thursday 6th November at the Holiday Inn near Padworth.

Some 45 people consisting of carers, speakers and Committee members came and enjoyed an excellent 2 course meal before settling down to listen to speakers on a range of topics relevant to carers of people living with MND.

Carol Allen, our Specialist Nurse, explained what she could do to guide, help and support people living with this condition and she was followed by OTs from the 3 parts of Berkshire West, namely, Wokingham, Reading and West Berkshire. Our own Jan Gryglaszewska then gave us a whistle stop tour of benefits, allowances and the all-important Continuing Healthcare Funding (CHC).

This was a lot to take in but delegates had been provided with folders containing a lot of information from all the speakers which we hope they will be able to read at their leisure!

Before the tea break, Mary Jacobs from Reading Crossroads explained what care there was available to enable carers to have some respite which was very helpful.

By now we were running a little late, but our speakers stayed and Dr Jane Bywater, Palliative care Consultant from Duchess of Kent Hospice talked about the nature of Palliative Care and what it is for. The time allowed was really too short and I, personally, would have liked to have heard more about this aspect of care.

She was followed by Tania Christie, the newly appointed Customer and Community Advisor for Scottish and Southern Power Distribution who is developing a database of people who would be very vulnerable in the event of a power cut, so that the company can react quickly if there is a suspension of energy supply. To be put on the Priority Services Register you need to call: 0800 294 3259.

Finally, Robert Monk from Berkshire REMAP gave us a very succinct presentation on the making of bespoke equipment for disabled people.

It was a really interesting day and the feedback was very positive. I enjoyed it and learned a lot myself, and so I hope the carers who came had the same experience.

Joanna Knott
On Thursday October 16th my colleague, Jan Gryglasewskia, and I drove up from Wokingham in Berkshire to Stratford’s Holiday Inn in good time to attend this year’s AV Forum. It was easy to find, had plenty of parking space and was a spacious and comfortable venue in which to attend the event. It was rather more special this year because it was going to be attended by our patron, HRH The Princess Royal.

After initial speeches by Chris Wade, Sally Light and Steve Bell we spent time looking at different scenarios concerning Diversity issues. The plwMND faced very different problems: one was an elderly man who lived alone in a very remote rural location, another was a single parent with 2 young children and the third was a Bangladeshi man who had little or no English and lived in a largely white area. We had all been allocated places at large round tables and were well mixed up with people from different areas – my table included AVs from Blackpool, Walsall, Taunton and Northern Ireland.

After the morning session, we repaired to the dining room for a very good lunch and a chance to catch up with other AVs – always a worthwhile experience!

On my way to the ladies afterwards, I couldn’t help noticing a red carpet being rolled out through the Hotel’s entrance and shortly afterwards two very busy hooverers making it look spick and span!

Back in the main hall, we were entertained to a video showing 13 different ‘celebrities’ taking part in the Ice Bucket Challenge and the challenge for us was to identify who these people were – they ranged from Benedict Cumberbatch and Sir Chris Bonninton to Zoe Ball and Fat Boy Slim – our table did not manage to win the prize of a box of chocolates! The game was included to fill time as Princess Anne’s programme was slightly behind schedule, but we were soon discussing the problems of children in families where a parent had MND.

When she arrived she moved around all ten tables and sat and listened attentively to what we were all saying, contributing and showing a real awareness and understanding of the issues. Afterwards she gave a short speech in which it was clear that she was really interested in the problems facing people with MND and it made me feel that our organisation is very fortunate to have such a dedicated and hardworking patron who does her homework and is keen to lend what support she can.

It was a most enjoyable day but, because of the Princess’ visit, much more tightly structured than previous Forums I have attended. Next year, I hope there will be opportunities for AVs to discuss more openly what is going on in their areas, what initiatives are happening and what we can do better to improve the lot of plwMND and their families.

Joanna Knott

Christmas Tea Party
in The Long Gallery at Englefield House
by kind permission of Mr & Mrs R Benyon, MP, our branch Patron

Monday December 8th, 2.30 - 4.30 pm

Come along and meet friends, old and new, have a natter, enjoy the beautiful surroundings of The Long Gallery and tuck in to a splendid Christmas tea.

If you haven’t already bought all your Christmas cards then don’t worry - MND Christmas cards will be on sale as well!
Jenko & The Bear walk for a cough machine

I have been asked to write a few words about my brother, Paul and my nephew, Ross, (known as Jenko & The Bear) and their second 80+ mile walk, but that presents me with a problem. Not writing a few words, but restricting myself to a few words. I will do my best, although I have always said that mere words cannot express how proud I am of them, and my sister-in-law, Lin.

Their intention was firstly to raise awareness of MND, and secondly to raise further funds towards a cough-assist machine to augment the funds already raised by previous walks/runs, together with the many fund-raising ventures organised by and/or participated in by Lin.

They set off from Bath at 9.00 am on Sunday17th August to walk the 87 miles along the Kennet & Avon Canal tow path, passing through Bradford-upon-Avon, Hungerford and Newbury, arriving at their destination, Reading, at 9.00 am on Thursday 21st August after a total of 24 hours actual walking time. On Wednesday they reached Newbury and we joined them, together with Lin, her friend/helper Sheila and a lady off a narrow boat - who gave a very generous donation - for a photograph by a Newbury Weekly News photographer.

As a result of the walk and the many many car-boot sales, fetes and other fund-raising events organised by and/or participated in by Lin they raised enough to buy the cough machine, and on Friday 1st October my wife, Chris and I were privileged to join them at the Royal Berkshire Hospital when they presented the machine to the hospital. At the same time Margaret Moss, Jane Gilbert and Jan Gryglaszewska of the MND Association presented three further machines bought by the branch.

Anyone who has visited their Justgiving site will have seen that they refer to me as The Legend owing to my attitude to my condition and things I do, but the salient point is I didn’t choose to have MND, I merely make the most of a bad job. They choose to do all the things they do….and it’s not just the time and effort: every penny they raise goes into the fund, they take nothing to cover their considerable expenses. So who is/are the real legend(s)?

Alec Jenkins

Carer’s Grant

Don’t forget that we have again been awarded the Carers’ Grant for this financial year. This means that any carer can apply for up to £300 towards something that would make a difference to their lives. So it could fund a short break away, a spa day, some gardening help, a trip to the theatre etc. If the money is not spent we have to return it the funder by 1st April 2015, so please think of what would be most helpful for you. Payment is made on receipts and if you want to discuss this with your Visitor (if you have one) or me then please do so.

Joanna Knott
0118 984 4495

Autumn update from the Jenkins Family

With the summer season now well behind us, we are now starting out on our Christmas plans.

Having handed over a cheque to buy a Cough Assist Machine we have now set ourselves quite a challenge for the forthcoming year. We aim to raise £3,500 by the end of August 2015.

I am still selling off the items which I “salvaged” from the Reading Festival this year, and with a few car boot sales and indoor markets we already have £800.

Our Christmas events are shown on the back page, and we would love to see any of you there. We have enough help, we just need your support.

Lin Jenkins
Respiratory machines gift to hospital

Four respiratory machines, costing £12,000, have now been handed over to the Royal Berkshire Hospital by the branch.

One of them was entirely funded by the efforts of the Jenkins family, from Tilehurst, who spent a year raising funds at car boot sales, fetes and sponsored walks, in honour of their brother and uncle, Alec Jenkins, who has lived with MND for 15 years. Alec, from Newbury, watched proudly as the four machines were presented to respiratory consultant Dr Grace Robinson in October.

He said: “They will make a big difference to a lot of people. I cannot describe how proud I am of Lin, Paul and Ross. I didn’t choose to have MND, I just make the best of it, but they chose to raise all their funds.”

The “cough assist” machines, which help to relieve oral secretions caused by MND, are based at the hospital and will be available for people to use at home.

An appeal was launched by the branch after it was revealed that the hospital only had one such machine in its respiratory department.

It is thought their use will help prevent distressing hospital admissions and, in some cases, early deaths. Eventually it is hoped the health service will see the benefits and provide many more of the machines as was the case in Oxford.

Chair Margaret Moss said: “The Reading and West Berks branch is pleased to be able to help provide these for people with MND who have need of one to make their life easier.”

Dr Grace Robinson (2nd right) receives the machines from (L to R) Jane Gilbert, Jan Gryglaszewska, Margaret Moss and Paul and Lin Jenkins.

She also thanked other generous donors including Waitrose head office at Bracknell, Berkshire Freemasons and Dr Kay Murphy.

A Royal Berkshire Hospital spokesman said: “This is a really generous gift which we are very grateful to receive.

These machines will be of great benefit to our patients.”

Jane Gilbert

To donate to the branch “cough assist” machine appeal visit:

www.justgiving.com/Reading-and-West-Berks-branch-MND-Association/

Christmas Cards, etc

Just a reminder with Christmas just around the corner (oh no! I hear you groan) that you can purchase MND Christmas merchandise through the branch. Cards are available at many of the fairs, etc listed on the back page or by contacting Mary Dodds - tel 0118 941 4956 or mazzadodds@hotmail.com. Every item sold benefits the branch.

MND cards can also be purchased at the many ‘Cards for Good Causes’ shops in our area, including Reading, Henley and Hungerford.

Used Postage Stamps

Do you know that used postage stamps still have a value?

One of our members has a buyer for these and so raises funds for us. If you would like to help, remove the stamp from the envelope with about 1cm around it thus providing an undamaged stamp for the collector.

Let one of us know you have stamps or bring them to a Drop In for us to pass on to our stamp collector!
Bob and Jan wed - by their Association Visitor!

A Newbury couple facing the future living together with MND have been married - by their Association Visitor who befriended them.

Jan Brown and Bob Williams first met West Berks deputy registrar Gill Weeks when she visited them in her other role as a volunteer with the Motor Neurone Disease Association. The couple made their wedding plans after Bob, a widower, was told more than a year ago that he had got the incurable neurological condition. He and Jan got on so well with Gill, who volunteers for the Association’s Reading and West Berkshire branch, that they hoped she would be able to tie the knot for them on their big day.

“It was very personal and very special”, said Jan after their marriage in September at Shaw House register office in Newbury. “Gill is great as our Association Visitor and she did a lovely job at the wedding too.”

She said getting married was on a bucket list drawn up by Bob, a 64-year-old retired accountant, after he was diagnosed with motor neurone disease in July 2013. Jan explained: “Bob wanted us to get married while he was still strong enough to enjoy the day. Now we will face living with MND together – it has made us much closer.”

The golf-loving pair, from Enborne Grove, did a sky-dive together earlier this year and Bob wants to do more flying activities and drive a steam train. They have just returned from a honeymoon cruising around the western Mediterranean and plan a golfing holiday in Portugal next year.

Jan, aged 48, who gave up work so they can spend their time together, says: “We don’t know how long we will have together so it gives us more time to make the most of life.” She and Bob, who were friends for a long time before they got together as a couple, are also enjoying spending time with his four grandchildren.

West Berks Superintendant Registrar Julie Young said couples are not able to choose their wedding registrars but as Gill was on duty that day she was delighted to be able to conduct the ceremony.

New Webmaster

Although Jan has given up work to spend more time with Bob she has landed a new role - website editor for the branch. I am very grateful to Jan for relieving me of this duty.

Jane Gilbert

A Christmas Concert

Yattendon Church
Wednesday December 3rd at 7.30 pm

This is a concert of Christmas music and readings and will be followed by wine and canapés

The Oxford Collutorium Choir
Conducted by Dr Will Orr
Organist: Jonathan Holl

Proceeds in aid of Jumbulance (providing holidays for disabled people) and Yattendon Church Restoration Fund

Tickets from Kay Murphy (01635 201254) or Yattendon Store (01635 201236)

Branch Publicity

Our branch publicity officer does a wonderful job! But Jane Gilbert’s role has suddenly increased hugely due to the fact that the branch now has Twitter and Facebook as well as the website and the Newsletter. In order to keep all these connected it would be helpful if there was someone to help. Methodical, organised, able to check and pass on information? Could that be you?

If it might be, please contact us (see back page)
All the fun of the fayre

More than 3,000 visitors flocked to the Duchess of Cambridge’s home village to enjoy the many stalls, one of Graham’s famous hog roasts or bet on the chaotic sheep racing. It was also the venue for several Ice Bucket Challenges with TV’s Chris Tarrant, who lives nearby, doing the soaking in front of a large crowd (see separate story).

Fundraiser Lin Jenkins raised the Association profile with her sell-out lucky bag stall and a team of branch volunteers helped out on the day and with the preparations.

West Berkshire Mencap, Alexander Devine Children’s Hospice, and Macmillan Cancer Care were also given £1,500 each, £750 was donated to Riding for the Disabled and the Anthony Nolan Trust received £250.

The event committee is now calling for new volunteers to aid the smooth running of next year’s August Bank Holiday Saturday event and Lin has already signed up to join the village’s hard-working team.

Jane Gilbert

Snakes Alive

We recently went on holiday to Hunstanton in Norfolk, staying in a semi-detached holiday cottage.

When we arrived I remained in the car whilst my wife went to open up before getting my wheelchair out.

She found the key in a safe right next to the entrance and unlocked the door. As she opened it something fell out at her feet, she jumped back then saw it was a rubber snake that some bright spark had left there as a joke .......... and then she realised that the “rubber” snake was actually moving. It was a real snake!! It had crawled under the overhang of the door but the step prevented it getting right inside.

By the time I had got out of the car it had crawled around the back of the cottages, so I was unable to follow to see whether it had the zigzag markings of an adder. In case it was an adder my wife went to the other cottage to warn them because they had young children. The chap went round the back and used his phone to check on-line to identify the species. It turned out to be a grass snake!

Alex Jenkins

Spread the word

Do you tweet or have friends on Facebook? If so, we’d love you to share the work of the Association on social media.

Helen Findlay is running the branch Twitter account – send her a message saying you are a branch member @MND_RWB. We also hope you like the new branch Facebook page – MND Association Reading and West Berkshire – set up by Mary Dodds.
Fifteen-year-old Amy Henshall has decided to put MND into Room 101 after she lost her beloved “Gramps” to the devastating disease.

Amy explained her case in her own extremely powerful words during a presentation to her classmates at The Holt School in Wokingham as part of their GCSE coursework.

It is very hard hitting and some of you may find her story upsetting.

Her grandma Val was happy to share Amy’s thoughts written after her husband Adrian lost his battle with MND in September last year – just 369 days after his diagnosis.

The entire Henshall family was supported by the Association during Adrian’s journey with MND and Amy resolved to make him proud of her by focusing on her exams.

For the record Room 101 was a torture chamber in the George Orwell novel 1984 in which the prisoner is subject to his own worst nightmare. Celebrities compete to assign their pet hates to the depths of Room 101 in a BBC TV series hosted by Frank Skinner.

Here are Amy’s reasons for banishing MND:

In May 2012 my Grampy was healthy, he was happy, he was passionate about life. A few months later in September 2012 he was diagnosed with a disease, he was hopeful, he was strong, he was positive, he never gave up. On September 28th 2013, 1 year and 4 days after the diagnosis my Grampy passed away. He had stayed strong when everyone else broke down, he stayed positive when no one else could, he stayed hopeful even when he knew there was no hope left, 1 year and 4 days, 1 year and 4 days is all it took for this disease to kill him.

This is why I want to put Motor Neurone Disease in Room 101.

You may be wondering what MND is? How can it kill someone so fast?

Motor Neurone Disease is a disease which damages the nerves in your body to a point where they can no longer function; this causes the muscles in your body to weaken so much that you can no longer do your daily routine.

It begins slowly, you start noticing small changes in your body, for example not being able to lift a weight that you used to to lift easily, dropping mugs by accident, tripping over your own feet, you begin to feel weak and start sleeping for longer than normal. It only gets worse from then on; in the next few months people suffering with MND will feel pain and discomfort throughout their whole body, their body will cramp and spasm, their joints will become stiff and will not work properly, they won’t be able to walk, feed themselves, drink on their own, strong, they still have the same brain that they’ve always had.

Now, imagine being in a white room, there is nothing in there except for you, you feel and see pain everywhere, you see a clock on the wall, it is ticking. You know your life is running out yet you can still think and still feel, but you cannot function, you cannot control it, you see your family outside of the room. They are crying, trying to help but they cannot, you see your family break, your Mum gets depression, your Dad gets stressed at everyone. Your siblings worry about you day in day out, but you cannot help them, you know they are upset but you cannot reach out and hold and comfort them. The worst thing is that you know it is you who has made them so upset, just imagine, that is what life is like for a person who has MND. This is the point when they finally break physically and mentally.

STATISTICS

MND can affect any adult at any age; more people are diagnosed over the age of 40 with the highest incident occurring between the ages of 50 and 70. Men are affected roughly twice as often as women.

Each year 2 people in every 100,000 people are diagnosed, Population = 7 billion, 140 thousand are affected right now.

Life expectancy is on average 3 to 4 years, however some can be shorter such as 1 year and others such as Stephen Hawking can live for over 50 years.

MND kills people physically but harms them mentally and it leaves behind an extremely bruised family.

It is incurable, aggressive and terminal.

This is why I believe it should be put in Room 101.

Amy Henshall
All aboard for The Three Peaks Challenge

In 2011 my Grandfather John Austin sadly passed away following his brave battle with MND. He lived with this condition for over 30 years, never moaning or complaining, but fighting his battle quietly and with strength. John was an inspiration to his family and friends, and it was the same inspiration that made me want to train as a Speech and Language Therapist to help people in the same position as him. I now work for the Community Based Neuro Rehab Team (CBNRT) in Berkshire.

At the beginning of the year I happened to mention to a few colleagues at work that I wanted to raise money for MND in memory of my Grandfather. My idea at the time was to take part in the 3 peaks challenge, that means climbing the 3 highest peaks in the British Isles - Ben Nevis, Scafell Pike and Snowdon in a mere 24 hrs!

This idea is now a reality and nine of us are due to take on this challenge in June 2015. The team is made up of Physiotherapists, Speech and Language Therapists, Psychologists, a Therapy assistant, my husband and best friend who knew my Grandfather.

We have 7 months to train hard to ensure we are fighting fit. A few weekends ago a few team members made it to Snowdon for a dry run and were practically knocked off our feet by 74mph winds so hopefully the conditions in June won’t be so ferocious!

We are all training hard and fundraising hard to make as much money as possible for the MND Association.

Please support us and track our progress by visiting our Just Giving page at: www.justgiving.com/NewburyNeuro-9.

I’m sure I speak for all nine of the team when I say that I feel slightly anxious about what we have signed up to, however, at the same time I can’t help but think that even the hardest and most painful step taken up those mountains doesn’t come close or compare to what my Grandfather lived through. It is that thought that motivates me and drives me to complete this challenge and raise money for this condition!

The picture above shows some of the team at the top of Beacon Hill on our first team training.

Wish us luck!

Lisa Goldsworth

Hair salon’s raffle was a cut above the rest

Generous customers at a Newbury hair salon have helped the Association to get ahead with its fundraising work.

Staff at Jason Palmer Hairdressing in Oxford Street ran a successful raffle during the Summer and have now donated £426 to the Reading and West Berkshire branch.

Salon manager Emily Cork said staff at the salon had asked their clients to suggest local charities that were close to their hearts or that they are involved with.

“When Motor Neurone Disease was mentioned it struck a chord as my uncle lost his battle with the neurological disease in July”, she explained. “He and his family had been supported by the MND Association’s West Berkshire volunteers throughout his illness.”

Jane Gilbert
Events Diary

Friday 21st / Saturday 22nd November
Wokingham Mayor’s Market in the Town Hall. This is the first year that we have been able to do both days. Open from 10 am - 4 pm each day.

Saturday 29th November
Yattendon Christmas Fayre - Village Hall - 10 am - 2 pm

Sunday 30th November
Whitchurch on Thames Christmas Fayre, Village Hall, Manor Road. 11 am - 3 pm

Saturday 6th December
Bradfield Christmas Market - Village Hall 10 am - 2 pm and THEN - in the evening Theale High Street, Lights/Market/Late Shopping etc from 6 - 8.30 pm

Sunday 7th December
Mapledurham Christmas Fayre - Playing Fields/Pavilion - 10 am - 4 pm

Monday 8th December
Christmas Tea Party in the Long Gallery, Englefield House. 2.30 - 4.30 pm

Saturday 13th December
Tilehurst Pop-Up Market (not confirmed as yet)

Sunday 14th December
Thatcham Community Market - Broadway Green - 10 am - 4 pm

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2 £7m ice bucket boost (cont)
3 Canal cruise was simply magic
   More ice bucket stories
4 Magnetoencephalography - Have you ever tried to say that?
   £1,500 windfall from Henley Freemasons
5 Royal County of Berkshire Show 2014
6 Carer’s Conference
7 AV Forum
   Christmas Tea Party
8 Jenko and The Bear walk for a cough machine
   Carer’s grant
9 Respiratory machines gift to hospital
   Christmas cards and used stamps
10 Bob and Jan wed - by their Association Visitor!
    A Christmas concert
    Publicity Officer
11 All the fun of the fayre
    Snakes alive
    Spread the word
12 Amy puts MND in Room 101
13 All aboard for The Three Peaks Challenge
   Hair salon’s raffle was a cut above the rest

Branch Contacts

Chair
Margaret Moss
0118 9470871

Treasurer
Ed Gryglaszewski
0118 9789069

Events Coordinator
Gill Selby

Secretary
Val Pearson
0118 9789063
valerie.a.pearson@btinternet.com

RCDA
Vacant

Publicity
Jane Gilbert
0118 9714172

Website
Jan Williams
p-jbrown@msn.com

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