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mnda motor neurone disease association

Reading and West Berkshire

www.mndrwb.org



News Letter

A knight to remember



It was truly a night to remember for a knight of rock and roll who is living with MND.

Businesswoman and musician Sophie Hill's tribute to her music-loving uncle Ian Hill has so far raised an amazing £3,633 for the Association.

Sophie came up with the idea of A Night to Remember for a Knight of Rock and Roll as her beloved relative had often come to her rescue during nights out in Newbury when she was growing up.

She says it started as an idea to give 62-year-old Ian, of St Mary's Road, Newbury, a fun evening and it immediately took off with people clamouring for the 300 tickets at £5 each.

"I'm really chuffed that it sold out," she said.

"Ian used to be my knight in shining armour on nights out in Newbury and has always been a big inspiration to me musically.

"He is without a doubt one of the loveliest, most easy going people I know, and his diagnosis has come as very sad news to all of our family and Ian's friends. But, in true rock and roll style, he is fighting it every step of the way, with a smile on his face, a glass of red wine in his hand and good music to his ears. I have never met anyone so brave."

Father-of-two Ian, went on stage to draw the raffle and had a big smile on his face all night at the Shaw Social Club gig on February 21. He enjoyed catching up with old friends while listening to many of his favourite songs with Sophie on guitar and vocals and brothers Cliff and Jeff Robertson on lead guitar and drums. (See photographs of Ian and Sophie on the back page).

Afterwards he wrote on Facebook: "What a great night . . .enjoyed every minute of it. It was a shame when it finished". Ian was also very happy that so much money had been raised for the branch as "they have been such a huge help and support to me already"

Online tributes have also been coming in for Sophie, who runs her own web design company in Newbury.

One person wrote: "thank you for a fantastic evening's entertainment, your singing was amazing. And well done on raising so much money for a great cause, it was so obvious that your uncle and everyone else was so proud of you."

Many people who were unable to get tickets were determined to show their support to Ian by making a donation to the Association.

Sophie said: "The Motor Neurone Disease Association has been an incredible source of help and support to Ian, and he speaks very highly of them.

"So, what better way to show our support and throw him a truly special night to remember, than gathering some of the finest musicians I know, all his greatest friends and family, putting them into a big room with a constant flow of alcohol and raise a load of money for a very special charity?"

To make a donation visit:
justgiving.com/KnightofRockAndRoll

Jane Gilbert



MND Association Regional Conference

On Sunday 1 February, I rolled up to the Hilton in Reading armed with photos, labels, leaflets and branch newsletters. It was the Regional Conference and the branch had been asked to help at the Volunteering Stall to show what we do hereabouts. This was the largest number ever attending one of these events.

Along with the usual signing in, looking at exhibitors stands, refreshments and greeting others of the 'MND Family' either known or unknown; it's always easy to talk and share experiences at these gatherings! A bonus for those of us from Reading Branch was that a former treasurer and his wife were there too - great to see them both.

Excellent speakers informed us of what the Association is doing to improve care and to campaign for better services and to raise awareness. One 'worker' showed how she campaigns - she wears all her MND badges on her lanyard to remind all she meets - simple isn't it? I always thought campaigning meant joining a demo somewhere.

A good lunch which, with random seating, meant meeting a newly diagnosed guy and his carer from not so far away and hearing afresh how hard that time is, prepared me for the final session: 'Latest developments in research'. We all know how important research is and try, hard as we might, to understand (and I consider myself of a scientific bent) it It is difficult to grasp the science, but not hard to follow (at the time); they are good speakers and passionate about what they do and we know that their work all contributes to that goal - a world free of MND!

It was good to meet so many from the Association from CEO, trustees, regional staff and support staff, AVs, carers, people living with MND and supporters from a wide area.

Overall a well worthwhile day - have you thought about going to one of these? Try it next time?

Margaret Moss

Paddy's bakes take the biscuit!





L to R: Sarah Wright, Tilly Lawson, Ella Wright, Jack Wright, Jasper Lawson, Jo Lawson

Volunteer Paddy Lunn's annual cake and cards sale has piled on more pounds for the Association than ever before.

Her latest tasty treats raised a magnificent £557 - thanks to help from her two daughters Sara Wright and Joanne Lawson, four grandchildren, and a host of friends.

For Ella Wright, aged 14, Tilly Lawson, 13, Jack Wright and Jasper Lawson, both, 10, the highlight of the day was counting the money!

Delighted Paddy said afterwards: "It was a great day, we all enjoyed it. We had some lovely donations to the raffle, the grandchildren made fudge and Christmas decorations."

Once again the sale at Paddy's Sonning Common home, near Reading, featured a selection of cards (pictured top left) with scenes painted by her late husband Rodney, a talented artist who scooped a national award for his colourful work days after losing his battle with MND.

This inspired Paddy to get prints of Rodney's work to sell as cards in aid of the Reading and West Berkshire branch. She is also a valued member of its management committee and is thrilled to learn that Henley Golf Club, where Rodney often played with a friend, who is now living with MND, has recently chosen the Association as its charity of the year.

Jane Gilbert

'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/thenews

Golden Wedding Anniversary celebrated



Peter and Pam Phillips thought of others as they celebrated their Golden Wedding Anniversary in September.

They held a party for relations and friends asking them to sponsor them on the Oxfordshire branch Walk in Blenheim Park instead of giving presents. Donations came in on the branch Justgiving site and lots more on the sponsor form amounting to £3000!

They thoroughly enjoyed the Walk and got together with friends and family for a splendid picnic afterwards in the grounds when it was all over.

Thanks to the Oxfordfordshire branch of the MND Association for this article

Swimming the Channel . . . . indoors

Father-of-two Ian Eggleton is determined to make a big splash in his bid to raise money for the MND Association.

During May and June he plans to swim 22.5 miles in his local pool – the equivalent of the width of the English Channel.

This works out as a challenging 1448 lengths in total or 181 lengths a week for Ian who has had six years out of the water until recently.

He says: "I am raising money for the wonderful MND Association which provides invaluable support to those suffering from MND and their families.

"This progressively debilitating terminal disease took my mother Christina on 28th June last year and I aim to finish my swim on the first anniversary of her death."

The 41-year-old architect who lives in north London will be cheered on by all the family at the finish in his home town of Reading. Afterwards his dad Ken, wife Colette, daughters Anna, aged 7, and five-year-old Elsa, wil go for a picnic in the town's Harris Gardens where a bench has been placed in Christina's memory.

His brother Stuart previously did a run and kayak fundraising challenge for the Association which was the equivalent of several marathons.

Ian says the branch support to his family was "absolutely wonderful" after Christina was diagnosed.

"To know you are not alone was so important. I want to support the Association and do all I can to help find a cause and a cure to see if we can stop this disease."

You can sponsor Ian in his Channel challenge at: www.justgiving.com/ianEggletonMNDSwim/

Jane Gilbert



Ian fundraising with his mum Christina in 2012

BG Group Donation towards 'Cough Assist' Machines

In mid December, I was invited to BG Energy Holdings in Thames Valley Park, Reading, to collect a £1,500 cheque towards the branch's appeal to buy four respiratory machines. The process started in April with a submission to them for consideration by the Community Involvement Team. Having heard no more, imagine my surprise when in September I heard that the branch had been chosen for inclusion in their short list. More information was duly sent to the group, and then in December the invitation arrived.

Of the charities involved, it seems that the MND Association had received by far the biggest proportion of votes and so got the larger share of the donation. Andrea Malcolm on behalf of the BG Group presented the cheque in an envelope and was much amused that I did not know how much it was for! But I am always delighted to accept cheques for any amount regardless! And £1,500 did make me smile!!



As the need for these machines to help people unable to cough up secretions was considered urgent by the branch we bought four earlier in the year from our own funds. We then launched an appeal for cash to cover their cost so this generous donation from the BG Group helps enormously - half the cost of one machine! No sooner were they given to the Royal Berkshire Hospital (in September last) than they were allocated to people living with MND.

Our thanks to the BG Group for their very generous donation toward this vital support machine.

Margaret Moss

Picture above shows Andrea Malcolm with Branch Chair, Margaret Moss, after the envelope was opened!

The Royal County of Berkshire Show
19 & 20 September 2015 at the Newbury Showground

We have an MND information and awareness stall at the show again this year. We also have a tombola stall at the show which is great fun to do and helps with fundraising. We need your help if possible please. We are looking for donations of any items that we can put on a tombola and I'd be delighted to call and collect.

My contact details are: Mary Dodds tel: 0118 9414956 or e-mail mazzadodds@hotmail.com

Huge charity sale
Saturday 21st March - 11.00am - 2.00pm
Beenham Village Hall.

Yes, we really do have enough to fill a hall! Simply masses of things to sell, including small furniture, bedding, clothes, china, craft items, books, puzzles, plants, kitchen items (large selection) gardening items, camping equipment (large selection)jewellery, clocks, chocolates and sweets. There will be refreshments on sale throughout the day. Please do pop along and support us, and tell all your friends as well.

Contact Lin Jenkins: 0118 9412738 or email rlp.Jenkins@Tiscali.co.uk

MND Parliamentary lobby

Helen Findlay, one of the Association's campaign champions, who lives in Thatcham tells how she was involved in a recent Parliamentary lobby. Helen runs the branch Twitter account - tweet her @MND_RWB.

My father, James lost his voice because of MND and if I had needed any further confirmation about the huge importance of appropriate communication aids for people living with MND then I received it while standing in the Speaker's Room in the Houses of Parliament.

I was there in January attending a reception organised by the MND Association. The event was held to launch a report from the All Party Parliamentary Group (APPG) on MND called "Condemned to silence: Inquiry into access to communication support for people with MND" that details the difficulties that people living with the condition are continuing to experience (the report can be viewed on the MND Association website : www.mndassociation.org).

The communications aid penny dropped in my mind with an almighty thud while listening to a presentation at the reception given by Sarah Ezekiel who is living with MND. She talked about her feelings and experience on being diagnosed and how the disease developed and eventually took away her voice. So how did she speak to us? She used Eyegaze equipment and opened up her world to everyone in the room through the power of speech. Eyegaze has given her a voice and also enabled her to continue with other aspects of her life – she uses it to paint pictures that can be seen on her website (www.sarahezekiel.com) and she is a frequent user of social media like twitter.

So you may think that such communication equipment would be available for anyone who needed it and wanted it, particularly as the NHS has already earmarked the money for use by people living with MND. Unfortunately, this has not been the experience for many people and barriers continue. Indeed, the APPG report says that currently, the NHS funds communication aids for fewer than half the people living with MND that need them. Also that sometimes whether a person is prioritised for assessment and treatment "often seems to be because of the goodwill of individual professionals and not because of a clear policy within the NHS."

I was invited to take part in the lobby as an MND Campaign Champion. The day also included a roundtable discussion about the contents of the APPG report that included the other nine champions who come from different parts of the UK. This discussion was held before the reception and also involved Madeleine Moon MP, chair of the APPG on MND and Sally Light, CEO, MND Association. The MND Champions comprise people living with MND plus family carers and ex-carers. During the discussion, many stories of frustration and anger came out about the enormous efforts it can take in order to get appropriate care and for practical aids, such as appropriate wheelchairs, to be provided when promised. There was a general outcry about the lack of awareness and understanding among professionals about MND and what it means and why it is that people cannot be left hanging on for a long time for care and equipment that is vital to them.

Around 50 Members of Parliament came to the MND reception in the Speaker's House plus a number of peers and researchers from MPs offices. The following day, Madeleine Moon MP was picked out by the Speaker on the floor of the House of Commons to ask a question during Prime Minister's Questions. She requested that the Prime Minister agree to have a meeting with her and other MND representatives to talk about why the NHS is withholding funding for communication equipment and to get rid of the barriers. In response, the Prime Minister agreed to a meeting.

Following this, arrangements for a meeting and setting a date were very slow in forthcoming and so the MND champions, with the assistance of the MND Association, took to twitter and bombarded the Care Minister, Norman Lamb MP, with continuous tweets all requesting that he meet with MNDA. After 24 hours of this continuous twitter bombardment, his office announced that he agreed to meet and a date has been set in March 2015. So there will be more to report after this.

The Ice Bucket Challenge and the film The Theory of Everything plus Eddie Redmayne winning an Oscar for his portrayal of Stephen Hawking have all helped to raise awareness of MND over the past year. But there is still a lack of understanding as to what MND means in practice for people living with it, the impact it has on their families and how important it is that care and support are speedily provided. The work goes on.

Helen Findlay



School's vital support for MND family

Berkshire mother Amanda Wooding's oldest son had just started his new school when his father was diagnosed with motor neurone disease.

The news was shattering for all the family but support from the MND Association and Pangbourne College was vital in helping them to cope with the difficult months ahead.



Tony and Amanda Wooding with Charlie and Phillip

Mrs Wooding, her husband Tony and sons Charlie and Phillip were also boosted by reading news of the wonderful fundraising work being done to help people living with MND.

"The school had been absolutely incredible and I think we have been extremely fortunate in a horrible situation," she said. "MND is with us forever and we need to become a part of it and work towards the possibility of getting rid of it."

Sadly Mr Wooding, a research chemist from Streatley died in April last year, aged 52. Since his diagnosis less than two years earlier he had been supported by the Oxford MND Care Centre and the Association's Reading and West Berkshire branch which helped provide items of equipment.

Pangbourne College, where Charlie, aged 16, and 14-year-old Phillip are pupils has collected nearly £2,000 to support the Association's vital work.

Housemaster Charlie Sutton and his wife Laura worked hard to organise a Call My Wine Bluff evening which raised £1,251 and a collection in the Falklands Chapel at the school amounted to £740. Mr Sutton "hopes this can be an annual event at the College in order to increase people's awareness of the disease and raise as much money as we can."

Mrs Wooding now has plans for an event at Goring and Streatley Golf Club as a tribute to her husband who loved sport and movement of which he was cruelly robbed.

She is also keen to raise awareness of MND and has shared this photo of the family taken in the Italian Alps on Valentine's Day in 2013.

She said: "Tony had lost all meaningful use of his right arm, his left was weakening and he had some signs of spasticity in his legs ..... He skied all week!"

"We went to the top of the mountains on a piste basher to have supper."

Jane Gilbert

WALK TO D'FEET* MND

PUT YOUR BEST FOOT FORWARD & STRIDE OUT
IN OUR FUN AND SOCIABLE WALK in the Newbury Rotary Sponsored Walk.

Are you up for the 2015 challenge?

Sunday 10th May 2015, a walk centred around Bucklebury and its beautiful countryside within a designated Area of Outstanding Natural Beauty, starting at the Victory Rooms between 11.00am and 12.30pm.

The route of either 8 or 5 miles will be fully signed and marshalled.

Walk with us to raise funds for the Reading & West Berkshire Branch of the MND Association or come for the fun of a group walk. Walk to d'feet* t shirts on the day (if you tell us in good time!) Small, medium or large? (Contact readingmnd@hotmail.com).

Rotary have an entry fee of £1 per walker on the day which goes to Rotary nominated charities.
More info about the walk on www.newburyrotary.org
Full route details available later

Margaret Moss



West Berkshire Therapy Centre

This centre is now open 28 hours each week, with an evening service planned to start in April, thanks to support from NHS Berkshire West.

There will be an open day on:

Saturday 18th April 12.00 - 16.00 hrs

when you are welcome to drop in and see the unique facilities that are on offer.

(Please contact us to make other arrangements if this time is not suitable for you.)

The **power-assisted exercise** service is helping people with physical and sensory impairments to keep more mobile, be more confident with tasks of daily living, manage weight better and improve general outlook, health and well-being.

7, Clerewater Place, Lower Way, Thatcham RG19 3RF
Tel: 01635 864561 www.westberkshiretherapycentre.org.uk

Your community Therapy Centre

Jenko & The Bear - Annual walk

This years challenge is The Cotswold Way. As it is over 100 miles we will be doing it in 2 parts starting at Chipping Campden on Tuesday 26th May. They will cover as many miles as possible over the next 3 days, hoping to arrive at Haresfield Beacon at tea time on 28th May.

We start again on Sunday 2nd August, ending up in Bath on Tuesday 4th.

They will be joined by Ross' fiancée, Danielle, on some of the days.

I will be assisted in the support car by my sister Ruth or friend Sheila.

We only seek sponsorship every other year, just raising awareness in between. This year we will be seeking as much sponsorship as possible.

Our family target for all the events we do this year, is a minimum of £3,500, but hopefully it will be nearer to £5,000.

Contact Lin Jenkins on 0118 9412738 or rlp.Jenkins@Tiscali.co.uk

Items wanted

I attend Car Boot Sales throughout the year, as well as the Charity Sale. I accept just about anything! Are you moving house, downsizing, offspring marrying or moving in together? Are any family members moving into residential care? Please remember me before throwing anything away. I can often collect. Even if items seem too small to worry about - I can make up sets. Things might be a bit tatty? Is there anything I can do to spruce them up, and then sell on? Unless things are really tatty, or broken, then hand them to me. I will decide if they are no good! Equally, any unwanted craft items. I always need a ready supply to make things to sell at craft fairs etc. This includes wool, fabric, buttons, ribbon, knitting needles, embroidery yarn - anything that you no longer need.

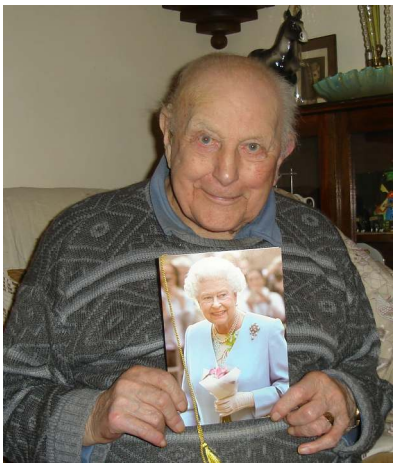
Contact Lin Jenkins on 0118 9412738 or email rlp.Jenkins@Tiscali.co.uk

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

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

100, not out



We hear so many stories about killings worldwide, people dying from some catastrophe or another, and, within the MND Association, someone who has lost the fight, so I thought It would be nice to hear about something pleasant. On Monday 12th January my Uncle Cyril celebrated his 100th birthday. Not only has he lived all that time in the same village, but at the same address.

I first knew him before he married my aunt and thereby became my uncle, when he and my father both worked on his father's mixed dairy/arable farm in Yattendon. Back in the early days they still used horses, as well as employing many rural skills long since lost. I remember the horses and I remember him thatching hay-ricks, and when was the last time you saw a hedge-row laid properly?

When his father sold up he went to work for Yattendon Estates. He enjoyed the work as it meant he was using much newer equipment: tractors, combine harvesters etc. In the meantime he had married my Aunt Gladys and she moved in with Cyril and helped look after his aging parents until they died, his father at the age of 99.

For his birthday it was thought better to have a 2-day informal "drop-in" on the Sunday and the Monday rather than risk tiring him with everyone coming at the same time. As it turned out nearly 50 family, friends and neighbours called in to wish him well, including the postman, the gardener, and many locals, all of which goes to show the affection in which he is held. He was delighted by the number of people who called in and the number of cards he received, particularly the one from Her Majesty.

Alec Jenkins

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A knight to remember

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Sophie Hill on guitar and vocals

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