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April 2020

motor neurone disease association

Reading and West Berkshire

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News Letter



Katie keeps on running in memory of her fun-loving dad



Teacher Katie Banks was undeterred when the Reading Half Marathon, which she planned to run in memory of her beloved dad, was cancelled due to the Covid-19 crisis.

She and her husband John still put on their MND Association vests on April 5th and went for a run around their home in Maidenhead instead where they were clapped by people who were out for their daily exercise.

Katie, aged 28, and a team of nearly 40 family and friends are now hoping the Reading run will go ahead as planned on November 1st. They have already raised an amazing £8,497 in aid of the Association and the fund is staying open.

She said: "This disease brought a helpless feeling but raising money has made us feel like we are fighting back."

Katie's sporty and fun-loving dad Win Patterson died in January, aged 59 – just ten months after being diagnosed with MND.

Mr Patterson, from Earley, had recently retired as deputy head teacher at St Crispin's School in Wokingham and was also fondly remembered as a popular and inspirational maths teacher by many former pupils.

Katie, who teaches P.E. at Reading's Abbey School, said: "My wonderful dad was tragically diagnosed at Easter last year and, true to his word, was an inspiration until the end. Everyday he made everyone laugh and managed to keep his positive outlook on life in spite of this unfair and cruel diagnosis.

"The MND Association has been a huge support to our family and we would love to give something back to the branch and support further research into treatments and cures for this disease in the future."

Katie, who got married last July, said her dad was determined to walk her down the aisle and gave an incredible speech at her wedding. She, her mum Sue, and two brothers have since been comforted by the many lovely messages from past and present members of the St Crispin's School community.

Once a keen runner himself, now Mr Patterson's children and many of his friends and family will carry on running to raise money for the Association to "help one day eradicate this awful disease."

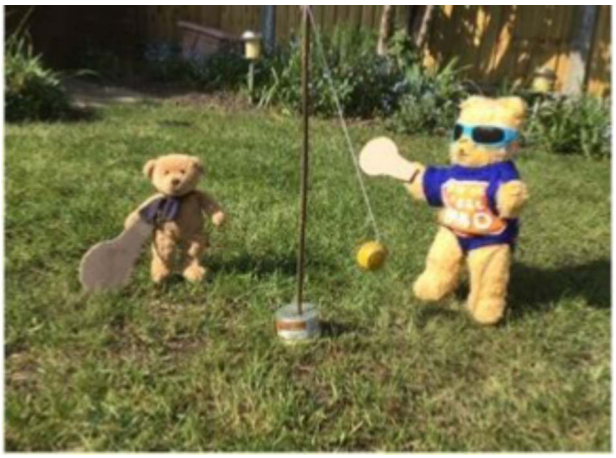
To sponsor Katie visit:

www.justgiving.com/fundraising/katie-banks7

Jane Gilbert



Teddy bears' lockdown picnic



Anyone for swingball?

These cute teddies have given us reason to smile thanks to Jacqui Warbey who wasn't going to let the lockdown stop fundraising in memory of her husband Richard who died nearly three years ago, aged 56.

Jacqui, who works for Newbury-based Vodafone, said: "In both the previous years I have organised a cake sale and raffle at work on the anniversary - a way of making something positive out of an otherwise sad day.

"However, with the lockdown in place I knew that I would have to think of something different this year.

"After a lot of thinking, I decided to use Goldie Bear (Richard's old teddy) and others that had been packed away after my boys no longer wanted them".

Jacqui, from Woodley, near Reading, shared photos on Facebook of the teddies doing different activities and set up an online fundraising page for donations to the branch. She was amazed to find she had raised £350 just over the Easter weekend.

Mum-of-two Jacqui searched the house and props and even knitted more clothes for the teddies to make the most of the sunny weekend weather.

She added: "I hoped it would give people a reason to smile and raise some funds for the branch which supported us."

Check out the branch Facebook page – MND Association Reading & West Berkshire - to see more photos of the bears having a ball.

To donate visit:

www.justgiving.com/fundraising/jacqueline-warbey1



We can help in so many ways. . . .

We are the Reading and West Berkshire branch of the Motor Neurone Disease Association, and we are your local point of contact. You might be surprised at how we can help you and people living with MND, their families and carers. We do a lot more than just providing voice banking, fundraising and organising the social events you read about in this newsletter.

We are all volunteers and most of us have had a close connection with MND. We work with professional health care providers to try and ensure people living with MND get the best possible care and advice. We also have a few hard working trained volunteer Association Visitors who can offer guidance and support.

Don't be shy, use the contact details so we can discuss with you how we might be able to help.

Email: ReadingMND@hotmail.com **Tel: 07760 854975**

Lin's honesty box stall helps community

When the lockdown began and all the years events gradually started to get cancelled, I panicked! Whatever would I do with all the stock acquired over the winter months ready for this year's car boot sales and fetes?

I then realized that families and individuals were ill equipped to be in lockdown for a long period of time.

I put these two things together and a plan began to form.

I live on quite a busy road with a small Co-op store and a chemist shop almost opposite our house. Dog walkers come by as do families and couples taking their daily exercise. This means that a huge footfall passes our gate every day.

I started off putting out box games, puzzles, books, CDs, DVDs and flowerpots. Two dozen large terra cotta flowerpots soon went. Then I went through all my supplies and put out as many craft items as possible. This developed more and more each day so that I rotated all stock in a minimum rota of three days for quarantine reasons.

The sweets and chocolates, kindly donated by Asda for Spring and Easter events, all went out. As I write, I am preparing cards and gifts for Father's Day.

I have already made loads of bunting, posters, flags etc for several big events I was due to attend as part of V.E. Day celebrations but they will not be wasted - I will use them to decorate our house instead!

I had a few items priced as a guide, but there was an Honesty Box on the table. At the end of each day, this box, the money, and all the tables, were disinfected.

The local community truly enjoyed this stall, and the comments, not to mention the awareness, were worth the effort of effectively having a car boot sale every single day for four weeks!

It was NOT about the money, but very much a community event. Therefore, I will not discuss how much I have taken until everything starts to go back to normal. I will then give a final figure.

Keep safe – and happy!

Lin Jenkins



Lin is pictured here in a teddy bear costume that she hopes will be worn at future events to help raise awareness of MND



Ginny has her cake – and eats it!

My friend Ginny England is one of our amazing cake bakers and is always on hand to donate one or two of her home baked cakes whenever we need one for fundraising.

When the branch's Art Café event on March 28th had to be cancelled in line with government guidelines Ginny and her husband Graham had only one option – to both eat her delicious cake themselves.

On Easter Sunday afternoon Ginny called me to say she and her husband Graham enjoyed the cake she had baked for Art Café and has donated £10 to branch funds.

We think their fundraising idea was a piece of cake!

Mary Dodds

Alec's lateral thinking lockdown challenge

Alec Jenkins has been living with MND for nearly 22 years and inspires us all with his cracking sense of humour.

The Newbury grandpa is also well known at branch events for his fiendishly difficult quizzes and has devised this brain teaser just for fun and to lift the spirits.

If players would like to send a donation to branch funds via **localgiving.org/rwbmnda** we would, of course, be enormously grateful.

Cheques, made out to the MND Association, can be sent to branch treasurer Ed Gryglaszewski, 27 Ashton Road, Wokingham, RG41 1HL.

If you'd like a copy of the answers please email **ReadingMND@hotmail.com**.

Good luck!

lateral-thinking challenge



1. Add a single letter to either the beginning or the end of the following sequence of letters to make an English word. You cannot change the order of the given letters. **LYLY**
2. Tom is Doctor Wilsons son, but Doctor Wilson is **not** Tom's father. Why?
3. Complete the following sum by placing either a + or a – in each set of brackets **123 ( ) 45 ( ) 67 ( ) 89 = 100**
4. Complete the word below by adding 7 letters. Letters may be added at the beginning &/or the end. The given letters must appear in that order in the final word, with no letters in between. **TANTAN**
5. If the following fractions are arranged in increasing order of size, which one is in the middle?
   [a] 1/2 ; [b] 2/3 ; [c] 3/5 ; [d] 4/7 ; [e] 5/9
6. Complete this word, using only three new letters. The given letters must appear in that order in the final word, with no letters in between **ONIG**
7. 2 fathers and 2 sons go into a café and each orders and eats a burger. When the bill arrived it showed 3 burgers only. There was no mistake on the bill and no special offer. How come?
8. Complete the 10-letter word by adding letters at the beginning **and** the end, with no letters in between. **HQ**
9. What letter comes next to complete this sequence? **O Ù E H R A**
10. You can see me in water, but I never get wet. What am I?

Alec

Former treasurer Barry Clouting fondly remembered

At the AGM in 2007, our then Branch Treasurer, Barry Clouting, retired.

He and his wife Carolyn had joined the branch in 2003 after a close friend had MND. Within a short space of time Lady Hallifax had worked her magic and he became our treasurer.

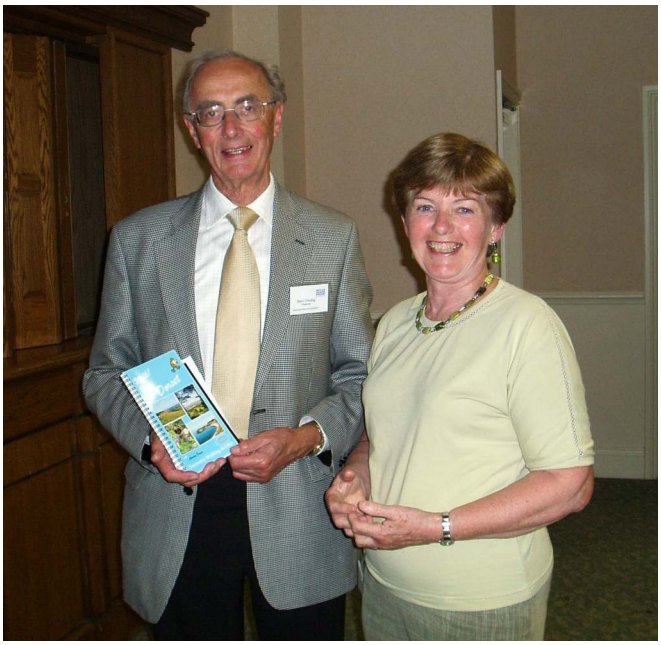
An efficient, capable and gentle man, Barry kept the books to the satisfaction of all including National Office. I recall spending time at his kitchen table emptying collecting boxes and endlessly dealing with the piles of coins and bags of cash.

Barry participated fully in our activities so when we were one of the charities to benefit from Snowdrop Sunday at Welford Park in 2005, he became one of the star marmalade makers, selling on the day in the cold, to help raise funds.

He was a lovely man and is remembered with affection for his time working with us. Barry and Carolyn have been very generous to the branch over the years.

They moved to the south coast after his retirement to join their family there and to be able to sail - another of Barry's interests. Of course, he joined the local MND Association branch there too and he was able to come back for one of our big events at Englefield House.

We were very sorry to hear that, after a short illness, he died on April 9th. It was not coronavirus related. The funeral will obviously be low key and a service to celebrate his life will be held in the future.



All our MND Association family here at Reading and West Berkshire branch are grateful for all Barry did to secure the future of the branch.

Thank you, Barry! We salute you!

Margaret Moss

Thanks Waitrose – from a distance!



It couldn't have come at a better time – a fantastic £428 donation during Covid-19 Lockdown from Waitrose & Partners store in Thatcham.

Kieran Tate, customer service advisor, kept his distance when presenting the cheque to branch publicity officer Jane Gilbert pictured at her home in Bucklebury

.

Jane said: "We are very grateful to all the customers who voted for us with their green tokens in the Community Matters scheme last year. It is a very welcome boost to branch funds which are inevitably depleted during this difficult time and will help us to continue supporting local people living with MND."

Lockdown thwarts chair's resignation!



In the last newsletter I said I would be resigning as Branch Chair at the AGM due to be held in March. It was cancelled as a result of coronavirus, of course, and will now be moved to 2021.

As a result, I haven't resigned; you still have me as chair of the branch! I am happy to continue in the interim given the circumstances, especially as the branch is operating at the minimum level of activity probably since the branch was formed all those years ago.

When the decision was made to cancel all face-to-face meetings - the AGM, the April Drop-in meeting, and normal life - I said to the others on the committee that it was a diabolical ploy to keep me on!

I believe one of them was heard to say: "She's rumbled us!"

However, I remain branch chair very happily - it's been a great chunk of my life in retirement and I have enjoyed it immensely, having met many wonderful people, those living with MND, those having lived with MND and all the committee members, past and present.

I feel very blessed to have been involved with the Association for so long and all the result of my brother having MND 20 years ago. I consider it his legacy to me and thank him for it. Good can come about from MND. Thank you all for all the support over the years. Your friendship and commitment mean a lot.

Footnote: We have recently had a nomination for Branch Chair which is very pleasing and welcomed by all the committee. However, the nominee Jane Westwell is currently Branch Secretary and until we recruit a new secretary, I will remain in post - you will see more information about this on the next page.

Margaret Moss

2019 was another solid year, says our treasurer



We were not able to hold the annual AGM in March due to Covid-19 restrictions. So, the best way to pass-on the branch's "financials" is via the Newsletter.

Here goes:

The branch received £44,000 in 2019 (2018: £48,000) by way of donations and fund-raising receipts. Thirty-three per cent of the total was through donations and 59% via fund-raising.

The branch's outgoings amounted to £49,000 (2018:£50,000). Of this, our annual transfer to the MND Association's central office was £24,000. So, our actual operating costs in 2019 were £25,000 (2018: £30,000). The £49,000 breaks-down as £14,000 for care-related costs, £9,000 for operational expenses and £26,000 transferred to central office (which was mainly 2018's annual transfer).

At 2019 year-end our bank balance stood at a healthy £169,000. It must be remembered that the branch bank account holds £121,000 by way of restricted funds, and our general-usage pot reduces to £24,000 (after taking account of the £24,000 2019 annual transfer). Our charter requires that we transfer 50% of our assets to central office annually.

We hold 4 restricted funds which are:

- an NHS-related expenses fund which has £500;
- an education/training fund with £500;
- a Jenkins Family fund for benefitting MND-stricken families which has £15,000 and
- a £105,000 Sheila Hamblin Legacy fund to provide MND-related help in West Berkshire. Please note this last fund depends on support and assistance from the MND Association's national office for its usage.

Overall, another solid year for the branch as we continue to function without any financial woes. May this continue well into the future!

Ed Gryglaszewski (Branch Treasurer)

Could you be the next Branch Secretary??

If you have administrative, organisational and IT skills you could be the perfect person to help our friendly and effective team. Our current Secretary Jane Westwell is stepping up to become Branch Chair - when her replacement comes forward!

The Branch Secretary provides secretarial support to the committee to help manage effective communications within this successful Branch.

What does this role involve?

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

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

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

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

Interested? Email the branch: **ReadingMND@hotmail.com** and we'd be delighted to talk about the role.

Everything is cancelled – but we're still here!

All our events might be cancelled but the MND Association's Reading and West Berkshire branch is still here to offer support and advice.

Our management committee met virtually for its April meeting with a video conference call and will carry on doing so until social distancing is relaxed. Our wonderful Association Visitors are also in contact by telephone or email with people they support.

Perhaps you'd like us to organize a drop-in meeting via Zoom? If so, email **ReadingMND@hotmail.com**



Get in touch with MND Connect on 0808 802 6262

MND Connect is available Monday to Friday between 9am - 5pm and 7pm - 10:30pm.

Calls to this number are free from landlines and mobile phones within the UK and do not appear on itemised bills.

Concern as MND left off Government's 'extremely vulnerable' list

MPs have been urged to put pressure on the Government to add MND to the list of 'extremely vulnerable' conditions for shielding vulnerable people from Covid-19.

The omission is causing a great deal of concern and uncertainty among the MND community and may result in them being excluded from additional support, the Association fears.

It says: "Until MND is explicitly added to this list, we are advising everyone with MND living in England to **register as a vulnerable patient**. The Government has said that people with MND can qualify under the 'severe respiratory conditions' sub-group on the self-registration list."

One of the main benefits of being on the list is that it is accessed by supermarkets and this should make it easier to get a delivery through on-line shopping.

Wendy Gouldthorpe, a branch Association Visitor, said she contacted several people she visited with this information, assuming that once they registered they would automatically be added to the list. "This has proved not to be the case," said Wendy.

Instead, people receive a standard text with the following wording:

> *GOV.UK coronavirus support: You registered as a clinically extremely vulnerable person. If you have not received a letter from the NHS or been in contact with your GP or hospital clinician, you should contact them to confirm whether you are considered clinically extremely vulnerable. If you meet the clinical criteria, your GP or clinician will be able to request that you be included.*
>
> *If you need urgent support such as food or care, please contact your local council.*

Wendy said: "This has left at least one person I visit feeling either that they're not believed, or that their condition isn't considered critical. They also now have to take another step and try to reach their GP or health care professional as described above.

"Not only are some GPs difficult to reach, but I've also heard of instances where the GP was not sure what action to take to get someone on the list. As we well know, people living with MND and their carers have enough on their plate without having to spend time and energy taking these extra steps. "

Newbury MP Laura Farris wrote to Public Health England after being told of the Association's campaign by branch publicity officer Jane Gilbert.

She said: "I also wanted to remind you that if your members need support they should contact the West Berkshire Community Support Hub on **westberksbct@westberks.gov.uk** or **01635 503579**. They will then be put in touch with community volunteers in their area who will be able to help with shopping, collecting prescriptions and so on."

Reading West MP and business secretary Alok Sharma replied to Mary Dodds letter about the campaign saying that GPs are currently identifying other patients who are clinically extremely vulnerable.

He wrote: "These patients will be contacted directly and will be advised to shield. This means that if someone with MND is identified by a GP to be clinically extremely vulnerable they will be added to the list and will be able to access the cross-Government support package. If you believe that you should be included in the extremely vulnerable group, you are advised to contact your GP."

Reading East MP Matt Rodda told branch Chair Margaret Moss he would follow developments in this area closely and bear in mind the points she had raised.

The Association maintains all people living with MND should be included on the list to avoid confusion and anxiety, and to ensure that there is a consistent approach.

"We are asking you, if you haven't done so already, please email your MP today. We need to up the pressure on the Government to add MND to their list."

Email your MP

TandemWoW are back – and the world is a different place



Those two amazing women – Cat and Raz – have broken the record for cycling around the world on a tandem.

Catherine Dixon and Rachael Marsden cycled more than 18,000 miles across five continents and raised more than £37,000 for the Motor Neurone Disease Association and Oxfam.

The two friends, both in their fifties, pedalled round the globe on Alice, their pink tandem, in 263 days, seven hours and seven minutes, beating the male world record of 281 days.

They said: "Just wanted to send a massive thank you for all the support, generosity and best wishes we have received.

"We will have a celebration once the virus concerns have settled down.

"In the meantime, thanks for following our epic journey and for your amazing support and please stay safe."

The awesome pair – who travelled between 80 and 100 miles a day through 25 countries – caught one of the last ferries from Caen in France to Portsmouth on March 17 and then cycled to Oxford to complete their record-breaking trip.

They originally planned to return a few days later but had to make their way back early due to Europe closing its borders because of coronavirus.

They cycled through the European heatwave of last summer, encountered flooding in India and South East Asia and had to change their route in Australia due to the bushfires.

Rachael Marsden, the Specialist Nurse and Care Co-ordinator at the Oxford MND Care and Research Centre, told the Press Association: "I think it has to be the most extraordinary time of my life.

"I absolutely loved every second of it. Cat and I just got on so well, laughed so much and just had a brilliant time every single day. It was brilliant."

She said they were able to complete the trip without losing a single day due to aches, pains or health issues.

And they had no support crew, so had to fix Alice the tandem by themselves and carry all they needed for the journey including camping gear, food, etc.

The record is subject to official verification, which will take a few weeks.

https://www.tandemwow.com/

Jane Gilbert



If you would like to change the way you receive newsletters (post or email) or if you do not currently receive your own copy and would like to be added to our mailing list (post or email)

please contact Jane Westwell:
07449 176173 or secretary_rwbmnda@yahoo.com

Tributes to dedicated neuro rehab doctor

Heartfelt tributes have been paid to Dr Peter Tun who sadly died on April 13th of Covid-19 at Royal Berkshire Hospital.

Father-of-two Dr Tun, aged 62, came to the UK from Burma in 1994 and had worked at the hospital for more than 21 years. He was an Associate Specialist in neuro-rehabilitation for people with complex disabilities like MND.

At the time the Newsletter went to press his wife was in hospital awaiting the results of her tests for coronavirus.

Dr Tun's family has blamed his death on the lack of protective equipment on his ward but this has been denied by the hospital.

Association Visitor Carol Allen had worked with Dr Tun at the Royal Berkshire Hospital during her career as a specialist nurse for rare and complex conditions.

She described his death as a great loss to friends, family, patients and colleagues whose lives he touched.

Carol said: "Peter was such a lovely, genuine human being, a most dedicated and knowledgeable doctor and willing mentor. He was always generous with his time, his knowledge and whatever he had to offer.

"He also looked after my son Jonathan when he was on Caversham Ward for several months and Jon has always spoken fondly of how he would go and talk to him about his musical tastes and playing the ukulele!

He truly is a great loss and will be remembered by so many friends, family, colleagues and patients whose lives he touched."



Dr Peter Tunn

I was shocked and deeply saddened to hear on the TV local news of the death of Doctor Peter Tun. I had not seen Dr Tun for a while but used to see him very often when attending Professor Christine Collin's clinic. On many occasions the professor was not available and so I would see him. He was a lovely man and we shared the same odd-ball and slightly irreverent sense of humour. We had many laughs together, but, don't get me wrong, he was serious when he needed to be.

Importantly, in 2002 I had a small stroke and it was found that I had Atrial Fibrillation - irregular heart rhythm - which probably caused the stroke. For several years after leaving hospital I was on several different blood thinners and it was Peter Tun who informed me about a procedure to correct it, called Ablation and, when I expressed interest, arranged for me to see someone from The Heart Hospital who subsequently performed the said procedure - successfully! Without Peter Tun I think it unlikely that would have happened and I would still be on blood thinners and/or have had another stroke, maybe more severe. I will continue to be grateful to him - and will never forget him.

I have no doubt that his family will be proud of him - justifiably so!

Alec Jenkins

For further information and support contact our MND Connect helpline mndconnect 0808 802 6262

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