

Reading and  
West Berkshire

[www.mndrdgwberks.freeuk.com](http://www.mndrdgwberks.freeuk.com)



Colin Moss: "Please spread the word so we can raise as much sponsorship money as possible and get as near as we can to Ashley's total."

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## Shortest Walk, Biggest Challenge

Colin Moss is preparing for his sponsored Shortest Walk but it may prove to be his biggest challenge.

Plucky Colin, who was diagnosed with MND seven years ago, hopes to cover up to a ¼ of a mile with rests every few yards. For him it is the equivalent of running a marathon as he has to use a walking frame and cannot walk at all, or even stand, without it.

Colin, aged 58, declared: "I have no idea how far I will get as I have not attempted anywhere near this distance for about four or five years."

The former semi-professional footballer is encouraging any people living with MND, who are just able to walk, to join him on Sunday August 30<sup>th</sup> in Reading's Forbury Gardens and raise money for the MND Association. Alec Jenkins, also living with MND, has confirmed he is able

to join Colin's walk.

Colin rose to the Shortest Walk challenge laid down by Ashley Morgan from Farnham in Surrey who raised £5,200 by walking 225 yards in 22 mins 5 secs.

Ashley's parents, Jim and Phyllis Swint of Virginia, USA, have now pledged to sponsor Colin - the first person to take up Ashley's challenge- for £100. Ashley, who is living with MND, is also sponsoring Colin for £25, and hopes to be there to support him. She says: "Congratulations on taking up my challenge! I am sure you will do a great job."

Supporters are welcome to cheer Colin along at Forbury Gardens from 2pm, where the Waltham St Lawrence Silver Band will be playing in the bandstand from 3pm until 4.30pm.

To pledge your cash click on the following link [www.justgiving.com/colinmossshortestwalkchallenge](http://www.justgiving.com/colinmossshortestwalkchallenge)

# Casablanca2London Picnic Party



The cyclists pictured (from left): Jack Gilbert, Sahaj Sethi, from Compton, who is back up driver, Chris Kroon, Ella Burroughes, Annelie Green, Richard Livesidge and David Green.

A picnic party and auction near Hungerford has netted more than £10,000 to help fight Motor Neurone Disease.

The successful event was held at North Hidden Barn on Saturday (June 27) to help boost funds being raised by a marathon cycle ride from Casablanca to London in August.

One of the cyclists, Annelie Green, from Kintbury, organised the party with her friend Jane Gilbert, who is a volunteer for the West Berkshire branch of the Mo-

tor Neurone Disease Association.

About 140 people enjoyed a picnic supper and danced to live band "Lucky to be Alive" after the auction which alone raised £7,300. Auctioneer Simon Fryer attracted keen bidding for the various unusual lots. They included a trip in a power boat with former British champion Nick Clemson of Hampstead Norreys which sold three times.

Among the helpers were the six mad cap cyclists

who have taken up the big challenge to pedal 1000 miles in 100 hours finishing at Tower Bridge on September 13<sup>th</sup>.

The outstanding success of the picnic party means they are well on their way to smashing the £12,000 target which will go directly towards ongoing research into MND – a devastating neurological disease which kills five people every day in the UK.



Michael Bell serves pudding to guests

Annelie Green is cycling with her husband David and son Chris Kroon, friends Ella Burroughes, Richard Livesidge, and Jack Gilbert, from Bucklebury, who lost his grand-mother to the disease.

She said: "I know we are mad but this cycle ride is a small challenge compared to the challenge people living with MND have to face."

The team set off on August 26<sup>th</sup> and are training hard on the lanes around Newbury and preparing for the final push to reach their fundraising target.



Pippa Vincent, Nick Wakefield, James Price and Sarah Lawes enjoy their candlelit supper.

To support the cyclists' quest, log onto [www.justgiving.com/casablanca2london](http://www.justgiving.com/casablanca2london)

*Jane Gilbert*

## Cake Sale for MND

**Lady Halifax writes a charming account of the fundraising enterprise of her grand-daughters and friends one wet weekend:**



Watch out Sir Alan! Our budding apprentices are (left to right): Silvy Chichester, Una and Maya Burmand

“Three weekends ago on a wet weekend my daughter and two youngest grandchildren Una, 11, and Maya, 9, decided to stay in London rather than come to stay with me. Una had invited her friend Silvy and they decided to

make some cakes to sell to raise some money.

They started by making flyers which were put through people’s letter boxes. They also made a large notice at the end of the street stating that a third of the proceeds would go towards the Motor Neurone Disease Association.

They then started cooking. They made 8 Victoria Sponges, Fairy Cakes, scones,

flapjacks and shortbread. I'm told the cakes looked very professional, filled with jam and cream, and sprinkled with icing sugar.

The telephone orders started to come in and Silvy took the first order for a Victoria Sponge.

“ Would you like a slice or a whole cake” asked Silvy. A whole cake was the reply. “Wow” said Silvy.

One lady ordered three whole cakes and another gave a donation of £10 because she had a friend with MND. There were many other donations and, as the weather was much better than forecast, the girls set up a stall at their gate and neighbours came by all day - many of them coming back several times. The girls also served cream teas from 4pm!

All three were delighted to have made £20 each and I was especially delighted to be presented with a jam jar full of notes and coins amounting to £44!”

*Anne Halifax*

## Spotlight on Volunteer Mary



Branch Newsletter Editor, Mary Watson, was featured recently in Thumbprint, the national magazine for the MND Association.

The feature highlighted the “behind the scenes” work of Mary, and other

volunteers nationally, for the charity.

Mary, formerly Marketing Manager for a software company, and currently a full time languages teacher and Head of Department at a Maidenhead Secondary School, says of the work she

does,

“The rewards are immense...but the main thing is how satisfying and enjoyable it is for me to read the stories that go into our newsletter, stories of incredible warmth and courage....

The Newsletter is a team effort—I couldn’t do it on my own.”

# Snowdon Walk to D'Feet MND

Walkers who battled with atrocious weather conditions on their journey up Mount Snowdon were inspired by a Berkshire woman who is fighting MND.



Some of the Mount Snowdon walkers with (seated l to r) Honeywell's Katy Guess and Cynthia Lynch.

About 60 people of all ages took on the challenge to help Cynthia Lynch from Bracknell and the charity that has supported her throughout her illness.

High winds, hail, rain and sleet may have stopped some in their tracks but the result was a fantastic fundraising effort with around £10,000 raised in total.

About half of that has been given to Cynthia, aged 60, who was born in Zimbabwe, to enable her to visit relatives around the world while she is still able to make the journey.

The rest is being given to the MND Association's Reading and West Berkshire branch to help fund its work in supporting people living with the disease.

Walk organiser Katy Guess worked with Cynthia at Honeywell in Bracknell until the weakness in her limbs made it impossible for her to continue. Soon after her diagnosis Cynthia's boss suggested staff

should raise money for her to go on her travels and Katy began marshalling the troops into action.

Cynthia's sister, Kathy Black from Eton Wick, said Honeywell had been "absolutely amazing" and she said Katy Guess especially deserved a huge pat on the back.

Kathy said: "I was so impressed with these people – they devoted a whole weekend to the walk. It was just amazing."

Conditions on the walk in May were so bad that several people had to be rescued and carried back down. Kathy, aged 64, was dubbed a "super gran" by her two grandsons who joined her on the trek after she attempted most of it and insisted on walking back.



Cynthia Lynch, right, receiving her cheque for £4,647 after the Snowdon Walk from Honeywell's Katy Guess.

Staff at Honeywell presented Cynthia with a cheque before she set off in June on her travels in Africa.

When she returns the pair plan to visit their sister living in New Zealand to complete the family re-union.

*Jane Gilbert*

# Community Matters to Waitrose

Customers at two Reading supermarkets have given a big boost to a charity's funds to help people living with Motor Neurone Disease (MND).

Caversham and Tilehurst branches of Waitrose.

Staff at both Caversham and Tilehurst branches of Waitrose chose the MND Association to benefit from their highly successful Community Matters project.

Margaret said: "Waitrose very generously chose the MND Association Branch for April - they like to help charities that work locally.



Branch chair Margaret Moss is pictured (right) receiving a cheque from Caversham manager Rob Skilliter. Also pictured is Mrs Paddy Lunn from Sonning Common whose husband Rodney was supported by the charity until he died in March, aged 67.

At the cheque presentation the staff were impressed to hear that Paddy (who they recognised as a customer) and Rod had been helped by our Branch in the Caversham area.

Under the scheme, shoppers are given a token at the check-out to give to one of three charities every month. The charities, in turn, receive cash from a £1,000 share-out based on the number of tokens collected.

We are delighted to receive such a large amount and thank all

The MND Association's Reading and West Berkshire branch was given £480 and £430 respectively from

the customers who supported us!"

*Jane Gilbert*

## Fields of Gold for MND



A mini metal detecting rally at a Berkshire stud farm has unearthed £1205 to help people living with MND.

members of the Newbury-based Wessex Metal Detecting Association including more than 300 bullets and a lot of military badges. It is thought the site had been used by the 101<sup>st</sup> Airborne Division, known as the Screaming Eagles, which had been active around the Berkshire/Wiltshire border.

to one of the organisers Trevor Sprules. He has been a great supporter of the MND Association since he lost his friend George Pearce to the disease.

The manager of the estate, Mr Richard Evans, said the prince had been delighted to help such a worthy cause.

The surprise donation came after treasure hunters were allowed to trawl the pasture land outside Hungerford courtesy of its owner, a Saudi Prince.

The branch is especially grateful to chair Jim Bradshaw, vice-chair Trevor Sprules, and Mick Turrill of Leisure Promotions in the Kennet Centre, Newbury, for their continued support.

A wealth of items from the Second World War was discovered by the delighted

Medieval coins and buckles and a few dog tags were also in the haul, according

*Jane Gilbert*

# Swine Flu Update

"Over the past few days we have developed our plans for maintaining services for pwMND in response to public health concerns regarding swine flu.

We are tracking the situation carefully and putting in place precautionary measures to ensure we focus on supporting the immediate needs of pwMND and protect them, carers, volunteers and staff from unnecessary exposure to the risk of contracting swine flu.

### Information for pwMND and their carers

Most importantly, we must ensure that anyone who thinks they may have contracted the virus is directed straight to the help they need.

The following letter has been sent to all branches of the Association by Kirstine Knox, Chief Executive. For up to date information on Swine Flu and MND, see [www.mndassociation.org](http://www.mndassociation.org)

We are signposting people to the NHS Choices website and NHS Direct helpline and its equivalent in Northern Ireland. We will also refer them to their GP or suggest they contact MND Connect who will give them the NHS advice.

We are regularly reviewing the latest health information from the Department of Health (DoH) and are updating our website as new information emerges.



A question and answer sheet for staff who have direct contact with pwMND and their carers has been developed. This seeks to answer what we anticipate will be frequently asked questions. Please see the document '[Swine flu information for people with MND and their carers](#).' This fact sheet will also be published on our website.

### Health of branch members and volunteers

We are naturally concerned with the health of branch members and volunteers. The information sheet referred to above also provides general guidance on how to minimise the risk of spreading

the virus by adopting good hygiene practices.

### Services for people with MND

In the event of staff absences owing to swine flu, we have identified the three essential services to maintain are MND Connect, Equipment Loan Service and Financial Support.

### Advice for branches and groups on running events

The document, '[Swine flu management: Information for branches, groups and volunteers](#),' provides guidance about running events. Ultimately everyone needs to be mindful of the risk that swine flu poses to people with MND and their carers. Local meetings are important to people with MND so a balanced approach when deciding whether to hold a meeting or event is advised.

### Events organised by national office

Public health advice to vulnerable people is to avoid large gatherings. The Board of Trustees has therefore endorsed the Directors' recommendation that we cancel **the Annual Conference** and we have also decided to postpone the **30th Anniversary event with HRH The Princess Royal**.

It is a legal requirement to hold an **AGM** and this will therefore go ahead on 12 September. We are investigating the possibility of webcasting the event to offer as many people as possible the opportunity to view proceedings, albeit remotely.

**Finally, we are aware that there are reports that some pwMND have already been affected. I urge everyone to do everything possible to minimise the risk of contracting or passing on the virus.**

We will continue to monitor the situation closely and provide you with updates as necessary. "

# For the wheel life!

Sharon Scihllerstrom of the MND Association is asking for feedback on some recent websites, one of which is [www.thewheelife.com](http://www.thewheelife.com)

The Wheel Life is a social network and a directory of companies and resources aimed at making life easier and more enjoyable for wheelchair users in the UK.

You can build a profile with pictures, videos, blogs and much more, chat online, discuss issues in the forum, check out what events are going on around the country and even sell items in a free classified section.

Check out also The Wheel Life Guide, an online directory for all things wheelchair related; Leisure and travel activities, shopping, dating, relaxing and lots of other

information to keep you entertained.

Sharon would also like to hear from you with anything you think is relevant to living life on four wheels - Activities going on in your local area, good websites that you have discovered, products that you find useful or couldn't live without and we can pass this all on to the wider wheelchair world.

Sharon is also looking for feedback on/reviews of the following websites:

[www.ricability.org.uk/consumer\\_reports/mobility\\_reports/car\\_measurement\\_guide](http://www.ricability.org.uk/consumer_reports/mobility_reports/car_measurement_guide)

[www.ableradio.com](http://www.ableradio.com)

You can contact Sharon at [sharon.schillerstrom@mndassociation.org](mailto:sharon.schillerstrom@mndassociation.org)



Walking the dogfish?? Courtesy of wheel-life.com



## Newbury Collection

On Saturday 27<sup>th</sup> June a team of fourteen volunteers collected a total of £680.62 in Newbury Shopping Centre. We were delighted with the generosity shown by the people of Newbury and it was surprising just how many people had friends or family affected by MND.

Our team consisted of Gwenda Charman, Mary Davidson, David Ennis, Alec

Jenkins, Joanna Knott, Mari Lewis, Ann Minks, Shan Mills, Sue Price, Elaine Reynolds, Ed and Jan Gryglaszewski, Reg Watson and myself. Thanks and well done to everyone!

Special thanks to Ann Minks who made all the arrangements with Newbury Council and even arranged two free car parking spaces for the day, courtesy of Camp Hopson. Several entertainers performed

throughout most of the day which helped to pass the time for those collectors nearby.

Collecting debutant Dave Ennis collected the most cash on the day! Dave has joined us recently as a volunteer for six months and has already made his presence felt on several projects. Well done and welcome aboard Dave!!

Colin Moss

## The MND Association is 30!

What lies behind the wonderful effective organisation we know today that cares for, works for, researches into and campaigns for those affected by MND?

In October 1979, from a small bungalow in Nottingham, the MND Association was begun.

All over England, Wales and Northern Ireland, the Association branches will shortly commemorate the 30th anniversary of the formation of the Association in various ways and at a time and day convenient for the branch or group.

The all embracing event will be a Lantern Event – individually or with a group of friends and

family, you can light your own lantern, put it in your window or on your loved one's grave. As a branch we shall celebrate the initiative of those who started it all, whilst remembering our loved ones who have lived and died with MND as well as celebrating the huge progress made in care knowledge and awareness over the years.

We hope you will all join us in this local yet national event. Lanterns will be provided (you can write your message or name on it) and we will let you know as soon as we have confirmed a suitable date and venue. We look forward to seeing you there.

Margaret Moss

## David plans New York Marathon

David Ennis writes:

"I am going to be running the New York Marathon on the 1st Nov 2009 and hope to raise as much money as possible for the MND Association.

Every penny I raise will go directly to MNDA. I am looking to run the event in under 4 hours. Please support me in raising money for this very worthwhile cause as MND can strike anybody at anytime.

Donating through JustGiving is simple and fast—your details are safe and your money is sent directly to the charity with Gift Aid reclaimed on every eligible donation. So it's the most efficient way to donate - I raise more, save time and cut costs for the charity. So please dig deep and donate now at:

[www.justgiving.com/David-Ennis](http://www.justgiving.com/David-Ennis)

## Diary Dates

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### Drop-in Meetings

St Luke's Church Hall  
Englefield Road  
Theale  
Tue  
15 Sept  
11.30am to 2.30pm

The Mansion House  
Prospect Park  
Liebenrod Road  
Reading  
Thurs  
8 Oct  
6.30 pm to 9pm

Rivertime Boat  
Trip for plwMND  
Wed  
5 Aug  
11am-1pm  
Boarding from 10.45am  
Places are limited so a draw will select those taking part.

Summer  
Tea Party  
Canoe Club  
The Warren  
Caversham  
Wed  
19 Aug

Shortest Walk  
with Colin and Alec  
Sun  
30 Aug  
2-3pm  
Forbury Gardens  
Reading

### Oxfordshire Branch Annual Walk

The Oxfordshire Branch of the MND Association hold their annual walk on **Saturday 12<sup>th</sup> September 2009** at **Cornbury Park near Charlbury**, the family home of Lord and Lady Rotherwick. Walks for all abilities.

Volunteers required to walk for the Reading and West Berkshire Branch. Registration £5.

Contact Val Pearson for sponsorship forms and registration.

### Branch Contacts

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